

**PARENTS OF INTELLECTUALLY AND  
DEVELOPMENTALLY DISABLED CHILDREN: THEIR  
KNOWLEDGE, PROBLEMS AND NEEDS**

**SYNOPSIS**

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## **CHAPTER 1**

### **INTRODUCTION**

The World Health Organization provides a definition of the word “disability” as having any limitation or incapacity to carry out a task in a manner regarded suitable for a human. One type of disability is Intellectual and Developmental Disability (IDD). The International Classification of Functioning, Disability and Health (ICF) defines disability as a broader term that encompasses impairments, limitations on activities, and restrictions on participation. It describes the unfavorable interactions that occur between individuals having health conditions (depression, Down syndrome, or cerebral palsy) and external and internal factors (like negative mindsets, inaccessible public places and transportation, and a lack of social supports).

Approximately 200 million of the more than one billion individuals with disabilities globally face serious functional difficulties. The rising prevalence of disability means that it will become a more significant issue in the years to come. This is due to the global rise in chronic illnesses like diabetes, heart disease, cancer, and mental health problems as well as population ageing and the increased risk of impairment in the elderly. Compared to people without disabilities, people with disabilities experience worse health, lower success in school, a lower level of income, and a greater incidence of poverty.

In the past, individuals with intellectual disabilities went by variety of names. The knowledge and societal prejudices of that era were reflected in these names. These people were objectified. This implies that their infirmity overpowered their humanity. Throughout history, individuals with Intellectual and Developmental Disabilities faced stigma, fear, persecution, and oftentimes ill-treatment. A stigma is a distinctive emblem or mark used to denote either a characteristic or a condition. This characteristic or condition is viewed as harmful or socially unacceptable. Those who experience stigma become outcasts in a society that isolates and rejects them. Language that stigmatises someone can have serious negative effects.

Individuals with Intellectual and Developmental Disabilities were commonly labeled as "idiots," "feeble-minded," or "retarded". Controversial discussions still surround the labelling and naming of the conditions of these people. The term "Intellectual and Developmental Disabilities" (IDD) has lately replaced the word "Mental Retardation".

The World Health Organization (WHO) and the International Society for the Scientific Study of Intellectual Disabilities have both adopted the term "Intellectual and Developmental Disabilities" (IDD). Because the term "Mental Retardation" has negative connotations and is stigmatized, the American Association on Mental Retardation (AAMR) was renamed as the American Association on Intellectual and Developmental Disabilities (AAIDD) in 2009 based on a vote by its members. IDD, as defined by the AAIDD (2010), is characterised by significantly below average general cognitive functioning that coexists with a deficit in adaptive behaviour and develops during developmental stage, negatively impacting a child's academic performance.

In India, parents of differently abled children struggle with poverty which is linked to their child's disability. Many families with children with disabilities earn much less than the below poverty line. Miles (2000) asserts that although poverty causes disability, in country like India, it's also plausible that poverty leads to disability. A state of simultaneous deprivation comes from the coexistence of poverty and disability. According to Padencheri & Russell (2004), in India, people with disabilities are still assumed to be unhappy and to have a poor quality of life, and disability continues to be regarded as a "tragedy" resulting in a "better dead than disabled" mentality. In India, the perception of a family regarding disability found in any member and the steps they take to prevent, treat, and rehabilitate them are greatly influenced by the cultural beliefs surrounding the condition. Parents in rural areas of India typically have negative and unrealistic hope for their differently abled child (Gupta & Singhal, 2014).

In India, there are between 0.22 and 32.7 cases of intellectual disability per 1,000 people. Children with IDD are becoming more and more reliant on their family members, especially their parents. As a result, they need greater assistance and support for a variety of needs. Reeta Peshawaria (1995) stated that 2-3% of the general population suffers from MR, now known as IDD. Thus, she opined that there might be about 10% of the general population in India to have child with mental retardation and hence parents having mentally retarded child need to develop coping mechanisms and manage the situation.

Upon discovering that a newborn has an Intellectual and Developmental Disability, parents are naturally upset. Avoidance is prevalent and has an impact on day-to-day living. A parent's hopes and expectations for their child must often be drastically altered when they learn that their child has an Intellectual and Developmental Disability, which is often not diagnosed until after the child turns one year old. They frequently struggle with protracted sadness, rage, guilt, and an inability to handle significant practical and financial issues. Some parents choose to ignore their kids, while others become overly preoccupied with raising them, neglecting other crucial facets of family life. Having a child with an Intellectual and Developmental Disability is always challenging for the parents. It has a negative inverse effect on their lives. (Abdul Hamid, 2021)

The family, which consists of parents, children, grandparents, and other relatives, is the framework within which children are cared for in our society, and it is thus the basic unit for the majority of IDD children. Everyone in the family can help disabled children grow and develop by educating, training, motivating, and supporting them. The family is the first social network for IDD children, and their early influence has a long-term impact. These days, the focus is not so much on what healthcare providers can do for the families of individuals with intellectual disabilities as it is on what the parents, especially those who receive support from community, can do for themselves.

## CHAPTER 2

### REVIEW OF RELATED LITERATURE

The researcher conducted one hundred literature reviews to formulate her current research. She did 60 reviews of the studies conducted in abroad and 40 literature reviews of the studies conducted in India.

Studies Conducted in Abroad					
Sl. No	Title	Author & Year	Journals/Books/ Links	Objectives	Major Findings
1	Parents' knowledge of their child with profound intellectual and multiple disabilities: An interpretative synthesis.	Kruithof, K., Willems, D., van Etten-Jamaludin, F., & Olsman, E. (2020)	<i>Journal of applied research in intellectual disabilities : JARID</i>	To look at what parents know about their child with profound intellectual and multiple disabilities and how they use it.	Parents used their knowledge in essentially two ways: firstly as experts, and secondly as advocates.
2	Parental perceptions of child behavior problems, parenting self-esteem, and mothers' reported stress in younger and older hyperactive and normal children.	Mash, E. J., & Johnston, C. (1983)	<i>Journal of consulting and clinical psychology</i>	To investigate how parents view the behaviours of their children; parenting confidence, and mothers' stress that comes with raising young and old, hyperactive and normal or average kid.	Parents of hyperactive children showed lower parenting self-esteem than parents of typical children. Mothers of hyperactive children reported feeling significantly more stressed out. Self-esteem of parents and views regarding the child problem were found to be inversely correlated

3	Investigating Education and Support Needs of Families Who Have Children with Intellectual Disabilities.	Cavkaytar, A., Ceyhan, E., Adıgüzel, O, C. & Uysal, H. (2012)	<i>Turkish Online Journal of Qualitative Inquiry</i>	To define the family needs due to having IDD children.	Needs were identified regarding social support systems, personal growth, child-rearing abilities, the adjustment process, knowledge of special education programs and school policies, and children's health.
4	The experiences of parents of children living with disabilities at Lehlaba Protective Workshop in Sekhukhune district of Limpopo province	Tigere, B., & Makhubele, J. C. (2019)	<i>African Journal of Disability</i>	To focus on the experiences and problems of parents in rural area of South Africa, who had children with various types of disabilities.	The majority of fathers did not wish to be associated with disabled children. The study also revealed a theme of stigmatisation of parents. Parents were atoning for the wrongdoings they committed or engaging in witchcraft, resulting in name labelling.
5	Parents Raising Children with Intellectual/ Developmental Disabilities in Jamaica: A Grounded Theory Approach	Lowers-Roach, M. (2021)	<i>Theses &amp; Dissertations. 106.</i> <a href="https://digitalcommons.molloy.edu/etd/106">https://digitalcommons.molloy.edu/etd/106</a>	To explore the challenges and experiences parents or guardians of school-age children with IDD faced in Jamaica.	The primary obstacle and underlying social problem parents encountered, was a deficiency of resources and assistance.

6	Being the mother of a child with Asperger's Syndrome: Women's experiences of stigma	Gill, J., & Liamputtong, P. (2011)	<i>Health care for women international</i>	To explore the experience of stigma and problems of mothers having children with Asperger's Syndrome (AS).	Mothers felt stigmatised by how other people saw them as well as their children due to the appearance and unusual behaviours of their children.
7	Intellectually Disabled Children and Their Parents' Problems: Preliminary Evaluation and the Suggestion of Effective Strategies.	Malekshahi, F., Rezaian, J., & Almasian, M. (2020).	<i>Crescent Journal of Medical and Biological Sciences</i>	To ascertain the psychological issues faced by the parents of children with intellectual disabilities	Families of IDD children dealt with a variety of emotional, financial, and educational challenges in addition to numerous social and psychological issues related to raising their child.
8	The experiences of mothers of children with Autism in Jamaica: An exploratory study of their journey.	Mann, A. R. (2013)	<i>USF Tampa Graduate Theses and Dissertations.</i> <a href="https://digitalcommons.usf.edu/etd/4722/">https://digitalcommons.usf.edu/etd/4722/</a>	To examine the experiences and problems of mothers caring for children with autism living in Jamaica, and to look at the needs that were unmet.	A lack of early diagnosis, inadequate local services for preschoolers and early elementary students, difficulties in accessing those available services, and a lack of parental understanding of the symptoms and risk status of autism spectrum disorder.

9	The experiences of parents raising children with developmental disabilities in Ethiopia.	Tekola, B., Kinfe, M., Girma Bayouh, F., Hanlon, C., & Hoekstra, R. A. (2023).	<i>Autism</i>	To explore the experiences of parents raising developmentally disabled children in Ethiopia	Parents' early detection of developmental delays or differences in their child were influenced by their cultural and religious beliefs, Single mothers had to deal with a variety of interconnected issues, such as poverty, stigma, and no social support.
10	Managing Stigma - the Experiences of Parents of Children with Intellectual Disability.	Niedbalski, J. (2021).	<i>Polish Sociological Review.</i>	To analyse the phenomenon of parents' managing the stigma of their child's disability.	Parents of differently abled children experienced stigma in relation to their offspring. Depending upon whether or not their child's disability is apparent, parents take different approaches to coping with stigma.
11	Caretaking Burden and Social Support: Comparison of Mothers of Infants with and without Disabilities.	Erickson, M. & Upshur, C. C. (1989)	<i>American Journal on Mental Retardation</i>	To see the differences between mothers of children with disabilities and without disabilities in their perceptions regarding the burden of child care.	Fathers of infants with disabilities did not perform more care- taking tasks, than did fathers of infants without disabilities. Mothers of infants without disabilities were significantly less satisfied than mothers of infants with disabilities.



12	Mental Retardation and Parenting Stress.	Siamaga, E. (2011).	<i>International Journal of Caring Sciences</i>	To study on parenting stress for having child with IDD.	Parents' mental health was significantly impacted by all types of IDD. Parents of children diagnosed with IDD frequently mentioned symptoms such as stress, anxieties and depression .
13	The First Year: the support needs of parents caring for a child with an intellectual disability.	Douglas, T., Redley, B., & Ottmann, G. (2016).	<i>Journal of advanced nursing.</i>	To characterize the support requirements of parents raising an IDD child during the first calendar year of life.	Three major areas of support needs were identified: emotional support, support for information; and assistance in establishing a connection with peer networks.
14	FAMILY SATISFACTION PROFILES OF MEXICAN PARENT WITH A CHILD WITH INTELLECTUAL DISABILITIES	Mendoza, P., Vera, N. J., & Hurtado, M. (2015).	<i>Revista Inclusiones</i>	To study the level of family satisfaction of parents in Mexico who had IDD child.	Parental support was found to be the most significant factor in the analysis related to sex.
15	The Parents' Acceptance of Their Children with Intellectual Disability: A Phenomenologic al Study	Abani, M., Anislag, R., Budiongan, G., Cagape, W., & Paz, C. (2023).	<i>International Journal of Research Publications (IJRP),</i>	To investigate about parents' real-life experiences with accepting their child's condition of IDD.	The impact of societal prejudices, stigma, and myths about parental acceptance and the family's wellness as well as the child's wellness was additionally highlighted by the study.

16	Developing Partnership: The Anson House Pre-school Project.	Beveridge, S. (1982).	In P. Mittler and Mc Conatchie. H. EVS parents and professionals and mentally handicapped people: Approaches to partnership,	To identify the needs expressed by parents having IDD children.	Parents of IDD children expressed the needs for respite care, self-help group initiation, daycare services training, and identification of community resources .
17	Effects of Parents' Training on Families of Children with Mental Retardation: Increased Burden or Generalized Benefit?	Baker, B. L., Laden, S. J. & Kashina, K. J. (1991).	American Journal on Mental Retardation	To investigate how parent training affects IDD children.	Parents expressed great satisfaction with the training programme. There was a slight but statistically significant drop in the number of reports of depressive symptoms, issues with parents and families, general parental stress, and discontent with the adaptability of the family.
18	Positive impact of intellectual disability on families	Baker, B. L., & Blacher, J. (2007).	<i>American Journal on Mental Retardation</i>	To examine how parents perceived the positive aspects of having IDD child.	Behaviour problems had inverse relationship with positive impact.

19	Marital adjustment in families of young children with disabilities: Associations with daily hassles & problem-focused.	Gavidia-Payne, S., & Stoneman, Z. (2006).	<i>American Journal on Mental Retardation</i>	To investigate how everyday hassles and stresses affected parents of IDD children with regard to problem-oriented coping mechanism and their marriage related adjustments.	Mothers were high on reporting more daily hassles than fathers did. Problem-focused coping remains same irrespective of gender. Fathers higher on reporting everyday stresses and hassles had lower usage of problem-oriented coping mechanisms.
20	Coping & Positive Perception in Irish Mothers of children with Intellectual disabilities.	Greer, F.A., Grey, I.M., & McClean, B. (2006).	<i>Journal of Intellectual Disabilities</i>	To study coping & positive perceptions of mothers of IDD Children.	Majority of mothers showed their agreement on statement that their children are their happiness resource and they feel fulfil with their presence in their life.
21	Exploring the Lived Experiences of Mothers of Children With Intellectual Disability in Ghana.	Oti-Boadi, M. (2017).	<i>SAGE Open</i>	To investigate the experiences of Ghanaian mothers of IDD children.	Mothers stated the significance of coping mechanisms, such as hope, support, and spiritual convictions, in helping them to raise their IDD children.
22	Factors related to positive perceptions in mothers of children with Intellectual disability.	Hastings, R. P., Allen, R., McDermott, K., & Still, D. (2002).	<i>Journal of Applied Research in Intellectual Disabilities.</i>	To investigate what factors were associated with mothers' favourable opinions of their IDD child.	Reframing techniques for coping was positively correlated with mothers' opinions regarding their IDD child as an expression of satisfaction or joy.

23	Parental Stress of Pakistani Families with Children who Have Developmental Disabilities.	Ramzan, L., Rashid, A., Aziz, S., Batool, S., Yaqoob, S., Khan, M. A., & Chughtai, A. S. (2022).	<i>Pakistan Journal of Medical and Health Sciences</i>	To determine the level of parents' stress experienced by Pakistani families raising IDD or ASD children.	Mothers and fathers of ASD and IDD children reported mental fatigue, indicating that the mental health of those families was significantly getting towards worse condition. Insufficient level of psychological wellness increased stress.
24	Emotional Trauma in Parental Involvement in Transitioning Learners with Intellectual Disabilities from Mainstream to Special Schools.	Lefakane, L., & Maseko, N. (2023).	<i>Trauma Care</i>	To investigate how parents perceive their role in helping students with IDD move from regular schools to special education schools.	Identifying the IDD students was very difficult having overwhelming, mixed feelings, due to parents' education and cultural background.
25	Not my dream': Mother's challenge of raising intellectual disability child in Vhembe district	Raliphaswa, N., Maluleke, M., & Netshikweta, M. (2022).	<i>Health SA Gesondheid</i>	To investigate and characterize the difficulties faced by mothers of IDD children.	Mothers of IDD children reported anxiety, panic, shame, and economic stress
26	Are parents identifying positive aspects to parenting their child with an intellectual disability or are they just coping? A qualitative exploration	Beighton, C., & Wills, J. (2017).	<i>Journal of Intellectual Disabilities</i>	To know whether parents could recognize the positive effects of raising an IDD child.	A stronger sense of dignity, altered priorities, a heightened respect for life, happiness in child's achievements, a deeper sense of spirituality, deeper connections, and the beneficial impact IDD children on the larger community.

27	Quality of life dimensions for adults with developmental disabilities: a comparative study.	Sheppard-Jones, K., Thompson Prout, H., & Kleinert, H. (2005).	<i>Mental retardation</i>	To study on the aspects of quality living for developmentally disabled adults.	When compared to the normal people, developmentally disabled people have a significantly lower quality living.
28	BEYOND ABILITIES: UNDERSTANDING the LIVED EXPERIENCES of PARENTS of LEARNERS with INTELLECTUAL DISABILITY.	Salinas, Q., & Tiamzon, B. (2022).	<i>Cognizance Journal of Multidisciplinary Studies</i>	To understand the living experiences of parents of IDD students.	Increased awareness of parenting experiences, challenges and strategies for coping up with the situation in the wonderful journey of raising an IDD child.
29	Parental stress attributed to family members with and without disability: A longitudinal study.	Baxter, C., Cummins, R. & Yiolitis, L. (2000).	<i>Journal of Intellectual &amp; Developmental Disability.</i>	To find out how parenting stress was related to family members who had children with disabilities as well as without disabilities.	Stress which was attributed by the parents to those disabled family members was nearly twice as high as that placed on the youngest sibling who was not disabled.
30	Survey the problems of families with mentally retarded child covered by Guilan welfare centers in 2010.	Abasi, S., Fadakar, K., Khaleghdoost, T., Sedighi, A., & Atrkar Roshan, Z. (2010).	<i>Journal of Holistic Nursing and Midwifery</i>	To ascertain the issues faced by families of IDD children.	65.7% parents had experienced financial difficulties.

31	Managing turning points and transitions in childhood and parenthood - Insights from families with disabled children in Norway.	Ytterhus, B., & Wendelborg, C., & Lundeby, H. (2008).	<i>Disability &amp; Society</i>	To find out turning points and transitions in the life of children with disabilities and their parents.	Parents of 3-6 year old IDD children experienced parenthood similar to parents of normal children, but they had difficulties during diagnosis and treatment.
32	Voices from parents on the sexuality of their child with intellectual disabilities: A socioemotional perspective in a Chinese context.	Lam, A., Yau, Ma., Franklin, R., & Leggat, P. (2022).	<i>British Journal of Learning Disabilities.</i>	To understand the attitudes and experiences of parents or caregivers in China with regard to sexual desires or requirements of their adult IDD son or daughter.	Parents were not allowing their adult IDD son or daughter to engage in romantic relations or have sex, and they were less concerned about sexuality.
33	Sources of Stress among Parents of Children with Intellectual Disabilities: A Preliminary Investigation in Saudi Arabia.	Aldosari, M., & Pufpaff, L. (2014).	<i>Journal of Special Education</i>	To identify the differences in daily life stressors experienced by Saudi Arabian parents of male IDD children.	Saudi mothers felt more stressed than Saudi fathers with regard to the parent and child bond, the distinctive characteristics of their child, and the parent's attributes.
34	Compound Caregiving: When Lifelong Caregivers Undertake Additional Caregiving Roles.	Perkins, E., & Haley, W. (2010).	<i>Rehabilitation psychology</i>	To investigate experiences of caregivers about compound caregiving and how their quality living was related to it.	Major difficulties experienced by caregivers, was having no time for personal developments, no support help from neighbours or friends, physical fatigue as well as stress.

35	Family Voices: Life for Family Carers of People with Intellectual Disabilities in Ireland.	Chadwick, D. D., Mannan, H., Garcia Iriarte, E., McConkey, R., O'Brien, P., Finlay, F., ... Harrington, G. (2013).	<i>Journal of Applied Research in Intellectual Disabilities</i>	To map the life experiences family carers of IDD people in Ireland.	Reported needs were proper intervention, timely and flexible support at critical times throughout their lives and access to support services, and proper information without fighting for those members.
36	Stress among Parents of Children with Mental Retardation	Islam, Md., Farjana, S., & Shahnaz, R. (2013).	<i>Bangladesh Journal of Medical Science</i>	To assess the levels of physical as well as mental stress experienced by parents of children with IDD versus parents of children without IDD.	Compared to parents of children without IDD, parents of IDD children had a considerably greater mental anxiety score. 67.5% fathers and 71.4% mothers of IDD children reported more mental anxiety compared to physical one.
37	Onset of maternal psychiatric disorders after the birth of a child with intellectual disability: a retrospective cohort study.	Fairthorne, J., Jacoby, P., Bourke, J., Klerk, N., & Leonard, H. (2015).	<i>J Psychiatr Res</i>	To understand the prevalence of new psychological disorders in mothers after the birth of their eldest child with IDD.	Mothers of mild to moderate level of IDD children for a cause that was unknown had around 2-3 times greater the prevalence of psychological disorders than those of mothers having no IDD or ASD children.

38	Exploring Resilience from a Parent's Perspective: A Qualitative Study of Six Resilient Mothers of Children with an Intellectual Disability.	Gardner, Jenny & Harmon, Tony. (2002).	<i>Australian Social Work</i>	To study the experiences of mothers of IDD children.	Mothers used networks of similar parents for sharing information regarding services. Mothers of IDD children stated the role of respite care facilities which helped them to take a break from tiring daily caregiving duties and provided them additional time for other family members who needed their attention.
39	Mental health condition of parents who have children with mental retardation and some interventions.	Yang, Q. Y., & Jing, J. (2006).	<i>Chinese Journal of Clinical Rehabilitation</i>	To analyze the psychologic health status, especially the influential factors and intervention conditions of parents of IDD children.	Parents' emotional condition for having IDD children are effected by many different factors and complex process.
40	Parental Stress and Coping Mechanisms in Rearing Children with Intellectual Disability: A Study Conducted in Kathmandu.	Shrestha, A., Adhikari, R., & Pokhrel, G. (2022).	<i>Birat Journal of Health Sciences</i>	To determine the stress and coping mechanisms experienced by parents of IDD children in Kathmandu.	The degree of coping mechanics and parents' educational attainment were significantly correlated. Mothers, parents without any formal schooling, as well as parents of IDD children under 17 or below, reported high levels of parenting stress.



41	Families with Intellectually Disabled Children.	Ow, Rosaleen. (1994).	<i>Asia Pacific Journal of Social Work and Development</i>	To study on the families with an IDD child.	The Findings suggested that the services provided should not be restricted to teaching functional skills to those individuals with IDD.
42	PSYCHOLOGICAL DISTRESS, PERCEIVED SOCIAL SUPPORT, AND LIFE SATISFACTION OF FATHERS AND MOTHERS OF INTELLECTUALLY DISABLED CHILDREN.	Arzeen, N., & Irshad, E. (2021).	<i>KHYBER MEDICAL UNIVERSITY JOURNAL</i>	To study the mental anxiety, support from society, and fulfillments in life of parents of IDD children in Pakistan.	Mothers suffered from greater mental stress, anxiety, and depression, whereas fathers stated higher levels of support from society and satisfaction with life.
43	Life Experiences of Mothers of Children with an Intellectual Disability: A Qualitative Study.	Budak, M. I., Küçük, L., & Civelek, H. Y. (2018).	<i>Journal of Mental Health Research in Intellectual Disabilities</i>	To investigate the experiences of mothers raising IDD children.	Not all mothers IDD children viewed their experiences with a negative mindset. Nearly all of them went through major changes in their social and familial relationships as well as worries about the future.
44	Parents' needs of children with intellectual disability.	Noman, A. A. A., & Yasir, A. A. (2022).	<i>International Journal of Health Sciences</i>	To identify the sociodemographic factors that were related to the needs of parents of children with IDD.	The material needs of parents of IDD children were the mostly required need, then there was cognitive needs, followed by social and emotional needs.

45	“I hope I’ll outlive him”: A qualitative study of parents’ concerns about being outlived by their child with profound intellectual and multiple disabilities.	Kruithof, K., Olsman, E., Nieuwenhuijse, A., & Willems, D. (2022)	<i>Journal of Intellectual &amp; Developmental Disability</i>	To study about the concerns of parents about their child with profound IDD outliving them.	The majority of parents of IDD children wished to outlive their offspring and associated that with the belief that their child's quality of life would have been declined after they had died.
46	“My greatest joy and my greatest heart ache:” Parents’ own words on how having a child in the autism spectrum has affected their lives and their families’ lives.	Myers, B. J., Mackintosh, V. H., & Goin-Kochel, R. (2009).	<i>Research in Autism Spectrum Disorders</i>	To explore the experiences of parents having children with Autism Spectrum .	The study discovered 15 negative themes as well as 9 positive themes. The combination of positive and negative themes was seen as a dialectical perspectives on meaningful life.
47	Parenting Stress, Child Behavior Problems, and Dysphoria in Parents of Children with Autism, Down Syndrome, Behavior Disorders, and Normal Development.	Dumas, J., Wolf, L., Fisman, S., & Culligan, A. (1991).	<i>Exceptionality</i>	To measure the differences in the feedback given by parents about dysphoria, parenting stress, and behavioural issues found in children.	Parents of children with behavioural issues stated that compared to other children, their child's behavioural issues were more severe.
48	Effect of early intervention on the development of mentally retarded children	Dhoot, H. (1992)	Doctoral Dissertation, SNTD Women’s University. <a href="http://hdl.handle.net/10603/119496">http://hdl.handle.net/10603/119496</a>	To examine what were the impacts that early intervention had, on IDD children.	In comparison to children who did not receive any intervention, the experimental group's early training was associated with better outcomes in various developmental domains.

49	Parenting Satisfaction and Self-Efficacy: A Longitudinal Study of Mothers of Children with Down Syndrome.	Gilmore, L. & Cuskelly, M. (2012).	<i>Journal of Family Studies</i>	To explore self-efficacy along with parenting satisfaction of mothers who had children suffering from Down Syndrome.	There were definitely some kind of major notable relationships between mothers' proficiency with characteristics of their kid and the style of parenting, especially in the way that was expected.
50	The Perceived Meaning of Life in the Case of Parents of Children with Intellectual Disabilities (in Polish).	Stelter, Ž. (2015).	<a href="https://www.diametros.iphils.uj.edu.pl/diametros/article/view/838">https://www.diametros.iphils.uj.edu.pl/diametros/article/view/838</a>	To understand how parents having an IDD child perceived their life.	The perceived meaning of life for parents of IDD children was related to the suffering experienced by those parents due to the limited intellectual ability of IDD child.
51	Relationship among Parenting Stress, Self Esteem and Social Support on Mental Retardation Child Mother's.	Jeong, C. & Seo, Y. (2016).	<i>Journal of Korean Clinical Health Science</i>	To verify the relationship among parenting stress, self-esteem and support from society when mothers have an IDD child.	The relationship between self-esteem and parenting stress, and between parenting stress and social support- both had negative relationship. The parenting stress and self esteem are highly related.
52	Experiences of parents of children with intellectual disabilities in the Ashanti Region of Ghana.	Badu, E. (2016).	<i>Journal of Social Inclusion</i>	To look into the experiences of parents of IDD children.	Managing behavioural challenges of IDD children and financial costs were the major sources of stressors for parents.

53	Quality of Life of Parents of Children with Intellectual Disabilities in Croatia.	Misura, A. & Memisevic, H. (2017).	<i>Journal of Educational and Social Research</i>	To study about the lifestyle of parents of IDD children.	A statistically marked major difference was there between the perceived lifestyle of parents of IDD children and parents of normal children.
54	Supporting Parents who have children with Mild Intellectual Disabilities in a Special Needs Class in Gauteng.	Fourie, J. & Roux, V. (2017).	<a href="https://www.researchgate.net/publication/320716749_Supporting_Parents_who_have_children_with_Mild_Intellectual_Disabilities_in_a_Special_Needs_Class_in_Gauteng">https://www.researchgate.net/publication/320716749_Supporting_Parents_who_have_children_with_Mild_Intellectual_Disabilities_in_a_Special_Needs_Class_in_Gauteng</a>	To investigate the support needs of parents who had children with mild IDD.	Parents needed an intense support from other parents, as well as, from the teachers. They required some guidance on the day-to-day challenges of parenting as well as professional advice regarding their child's disability and future plans.
55	Parents' Perceived Behavior Problems in the Persons With Mental Retardation: An Analysis for Parents' Need.	Jalan, R. K., Adhikari, J., Belbase, M., Khan, T. A., Gupta, V., & Sinha, U. (2017).	<i>Journal of Nepalgunj Medical College</i>	To examine how behavioural issues in individuals with IDD correlate with degree of severity, sexuality and age.	When it comes to sex, males were more likely to disobey than females were to physically harm others. Parents wanted assistance primarily for dealing with issues related to disobedience, unusual behaviour, and the then issues related to physical harm to other people.

56	Prevalence of psychological distress among parents of children with intellectual disabilities in Malawi.	Masulani, C., Kauye, F., Gladstone, M., & Mathanga, D. (2018).	<i>BMC Psychiatry</i>	To ascertain the risk factors and frequencies of psychological distress among Malawian parents of IDD children.	Among parents of IDD children, no source of emotional support strongly predicted psychological distress.
57	Rewards and challenges of parenting a child with Down syndrome: a qualitative study of fathers' perceptions.	Sheldon, J., Oliver, M., & Yashar, B. (2020).	<i>Disability and Rehabilitation</i>	To examine the benefits and difficulties of raising a child who had Down syndrome focusing on fathers' points of view.	Fathers rarely reported financial stress or the negative behaviours of their child. Many fathers reported speech problems faced by their children.
58	Understanding mental health outcomes related to compassion fatigue in parents of children diagnosed with intellectual disability.	Davenport, S. & Zolnikov, T. (2021).	<i>Journal of Intellectual Disabilities</i>	To investigate psychological implications in parents of IDD children.	As the parents learned about the disability in their child, the results showed that their very first emotional reactions were a mix of grief, worry, and Contentment with compassion.
59	Resilience and Parenting Stress in Mothers who have Children With Mental Retardation during the COVID-19 Pandemic.	Indriasari, F. (2022).	<i>Jurnal Keperawatan Soedirman</i>	To study the effects on anxiety and endurance in mothers of IDD children during COVID-19 period.	The findings revealed that there was an influence of parenting stress on the resilience level of mothers having IDD child during the covid-19 period. The study showed, though mothers' anxiety level was low but mothers' endurance level was moderate.

60	Level of Depression in Parents of children with intellectual disabilities in District Swabi, Pakistan.	Ahmad, Z., Afnan, Z., Shabir, J., & Ahmad, B. (2022).	<i>Journal Riphah College of Rehabilitation Sciences.</i>	To find out how depressed the parents were and how psychosocially connected they were with their IDD children.	Single mothers having IDD children were found to be more depressed than mothers living with their spouses.
61	Exploring correlates among Latino/a parents of young children with intellectual and developmental disabilities.	Rios, K. & Burke, M. (2023).	<i>Autism research : official journal of the International Society for Autism Research</i>	To investigate the relationships among empowerment, anxiety, disability type in the child, and special education knowledge in parents of IDD children.	Parents, due to having an autistic children, reported much higher levels of anxiety and also knowledge about special education.
62	Parental Attitudes Towards Mental Retardation (A Field Study on the Families of Children Enrolled in the Social Welfare House in Al Bayda City).	Abdalrazek, H. (2023).	<a href="https://www.researchgate.net/publication/372061684_Parental_Attitudes_Towards_Mental_Retardation_A_Field_Study_on_the_Families_of_Children_Enrolled_in_the_Social_Welfare_House_in_Al-Bayda_City">https://www.researchgate.net/publication/372061684_Parental_Attitudes_Towards_Mental_Retardation_A_Field_Study_on_the_Families_of_Children_Enrolled_in_the_Social_Welfare_House_in_Al-Bayda_City</a>	To identify parenting attitudes towards their Intellectually and Developmentally Disabled children	Most of the parental attitudes were initially characterized by the discrimination between the IDD child and his or her non-disabled siblings.

#### Studies Conducted in India

Sl. No	Title	Author & Year	Journals/Books/ Links	Objectives	Major Findings
63	Magnitude of problem of persons having intellectual disability its impact on parents and their unmet needs in Indian subcontinent.	Bhattacharya, R., Ghoshal, M. K., & Sanyal, D. (2015).	<i>Bengal Journal of Psychiatry</i>	To examine the disability status of IDD persons as well as the nature and to what extent it impacts their parents.	In the areas of physical care, health, career sibling effect, and specific thought domain, mothers faced more challenges than fathers. Whereas, fathers had more difficulty in the areas of support, finances, social interaction, and embarrassment or humiliation.

64	Impact of children's intellectual disability on parents.	Chhotaray, S. (2020).	<i>The International Journal of Indian Psychology</i>	To study about various impacts that IDD children and their disability had on their parents' life.	While both parents were adversely impacted by their child's disability, mothers were heavily impacted.
65	Stress coping ability of parents of mentally challenged children.	Vijila, S., & Sreelatha, S. (2022).	<i>International Journal of Health Sciences</i>	To examine how well parents of IDD children coped with stress.	Almost 60% parents of IDD children had moderate stress coping ability.
66	A study on knowledge, attitude and practice on child-rearing among parents having children with intellectual disabilities in thrissur district kerala.	Jubina Bency, A. T., John, George., Navya, C.J., & Saju, C.R. (2017).	<i>International Journal of Current Advance Research</i>	To evaluate the parenting practices, attitudes, and knowledge of parents of IDD children.	The knowledge level among mothers who had higher educational was found to have high statistical significance. Compared to parents of consecutive birth orders, parents who had an IDD children in their first birth showed a higher knowledge level.
67	Awareness on different aspects of Intellectual Disability among caregivers.	Purty, S., & Singh, A. R. (2018).	<i>International Journal of Research in Social Sciences</i>	To ascertain the level of knowledge among caregivers of IDD children regarding various aspects of IDD.	Caregivers with lower levels of education had higher levels of misconception in each of the three domains of awareness compared to those with higher levels of education or at least a matriculation.
68	A study on the problems faced by the parents in handling the mentally challenged children in	Shetty, L., & Menezes, S. (2013).	<i>Global Journal of Interdisciplinary Social Science</i>	To explore the problems and issues that were faced by parents of IDD in Mangalore, India.	50% of respondents from non-urban localities thought that their child's condition was brought on by the evil eye, 16.67%

	mangalore district.				thought that the condition was something the mother had developed during her pregnancy, 5.56% thought that the condition was hereditary, and 27.77% thought that the condition was caused by an injury sustained during childbirth
69	A STUDY ON LEVEL OF AWARENESS ON ETIOLOGY OF INTELLECTUAL DISABILITY AMONG PARENTS OF CHILDREN WITH INTELLECTUAL DISABILITY.	Kapil, Y. & Selvan, T. R. M. (2017).	<i>Scholarly Research Journal for Interdisciplinary Studies</i>	To determine the level of awareness among parents having IDD children related to the medical and etiological factors of IDD.	The awareness level had no difference on the basis of the gender of parents. The awareness level did not have significance effect too on he basis of socio-economic status of those parents.
70	Parental knowledge regarding mental retardation and special education.	Khatib, J. M., & Khatib, P. B. (2014).	<i>Karnataka J. Agric Sci</i>	To understand parents' knowledge about IDD and the importance of special schools.	88.33% mothers lacked knowledge about disabilities.
71	Parents having Intellectually Disabled Children: A Systematic review of Quality of Life and Mental wellbeing.	Hameed, A. P. V. (2021).	<i>IJIRT</i>	To recognize the lifestyle of parents, the intervention strategies provided to them as primary caregivers of IDD children.	Older parents of IDD children had a low quality of life, and while social support services were offered, they were insufficient to meet the high needs.
72	Resilience and impact of children's intellectual disability on Indian parents.	Rajan, A. M., & John, R. (2017).	<i>Journal of intellectual disabilities</i>	To examine parental resiliency and its connection to the effects of a child's disability.	Raising an IDD child presented both pleasant and unpleasant experiences for the parents. Positive attitudes



					toward the child's handicap served as a protective factor, while negative ones served as a risk factor for resilience.
73	Needs of Indian parents having children with intellectual disability.	Verma, Rajesh & Kishore, M. (2009).	<i>International journal of rehabilitation research.</i>	To understand the combined needs of both parents of IDD children.	The needs differed according to the sex and also age of the IDD child. The study showed that severity of IDD had less effect on parents' needs.
74	Parents of Intellectually Disabled Children: A Study of Their Needs and Expectations.	Sahay, A., Prakash, J., Khaique, A., & Kumar, P. (2013).	<i>International Journal of Humanities and Social Science Invention</i>	To concentrate on familial requirements from the viewpoint of parents of IDD children.	Parents referred to strong needs about information of current and future service available in society and the community
75	A Study on Parental Attitude and Needs of the Parents Having Children with Intellectual Disability.	Wagh, S. D., & Ganaie, S. A. (2014).	<i>International Journal of Clinical Therapeutics and Diagnosis</i>	To evaluate and comprehend the needs and attitudes of parents of IDD children	Needs and attitudes were interconnected; when parents had a favourable attitude towards their kids with IDD, they showed greater needs and care.
76	Social Burden in the Families of Mentally Retarded Children.	Mamta. & Punia, S. (2003). In Singhal, C.S. (Ed.).	<i>Behavioural Management in Rural Development.</i> Ambala: The Associated Publishers.	To analyse the parental knowledge about IDD on the basis of background of residential area and socioeconomic status.	Parents had high and moderate knowledge on all aspects except facilities available. Socioeconomic status and residential area made a significant influence on the knowledge of the parents.

77	Knowledge of family caregivers on care of mentally challenged children at selected institution, Bangalore: A descriptive study	Vijayarani, M., Balamurgan, G. & Kasthuri, G. (2016).	<i>International Journal of Applied Research</i>	To assess the level of knowledge of family caregivers towards IDD children.	Majority of 78% of the family caregivers had inadequate knowledge.
78	Attitudes of Parents towards the Behavioural Management of their Children with Intellectual Disability.	Mushtaq, A., Inam, A., & Abiodullah, M. (2015).	<i>Disability, CBR &amp; Inclusive Development</i>	To understand the a attitudes of parents of children with intellectual disabilities, with regard to the management of problematic behaviour of their children,	While mothers had more positive attitudes than fathers, there was no significant difference between the negative attitudes of fathers and mothers towards their children with intellectual disability.
79	Parental Attitudes Towards Children with Mental Retardation: Across Sectional Study from NGOs in Northern India.	Mohammad, S. & Osman, A. (2015).	<i>Int J Res Health Sci</i>	To explore the attitude of the parents towards their children with IDD.	There was a parental negative attitude towards children with mental retardation which is highly on home management and lowest on acceptance.
80	A cross-sectional study on stress perceived by families of mentally retarded children enrolled in special schools of a city of central India.	Chourasiya, S.K., Baghel, A., Kale, S., & Verma, A. (2018).	<i>Int J Community Med Public Health</i>	To study on the stress perceived by families of IDD children.	32% of mother feel mild stress of which 59.3% having education level up to degree college. 61% of mother showing moderate stress of which 68.8% having education level up to Degree College.
81	The mental attitude-childrearing link for mentally retarded children: A study	Behari, R. (1990).	<i>Disabilities and Impairments</i>	To study the attitudes of mothers of mentally retarded boys towards 23 areas of child	The attitudes of educated mothers were significantly different from those uneducated mothers

	of some socio-psychological influences.			rearing as influenced by their strata and education.	
82	The Relationship Between Challenging Behaviour, Cognitions and Stress in Mothers of Individuals with Intellectual Disabilities.	Rose, J., Nelson, L., & Hardiman, R. (2016).	<i>Behavioural and cognitive psychotherapy,</i>	To assess the relationships between maternal stress, challenging behaviour of IDD children and parental cognitions.	Results indicated significant correlations between challenging behaviour and maternal stress. The overall mediation models for aggression and self-injurious behaviour were significant.
83	Parent Stress and Perceptions of Language Development: Comparing Down Syndrome and Other Developmental Disabilities.	Smith, A. L., Ronski, M., Sevcik, R. A., Adamson, L. B., & Barker, R. M. (2014).	<i>Family relations</i>	To examine differences in parental stress and parental perceptions of language development among parents having children with Down syndrome and Other Developmental Disabilities.	Children in both groups showed similar language skills, the parents of children with Down Syndrome perceived their child's communication difficulties as less severe.
84	Stress among Single Parent Families of Mentally Retarded Children.	Upadhyay, G. R. & Havalappanavar, N. B. (2007).	<i>Journal of the Indian Academy of Applied Psychology</i>	To investigate the support of spouses and stress levels among the parents of IDD children.	Widow and widower single parents had significantly different stress levels in all four stress areas: care, emotional stress, financial stress, and social stress. The stress level of single parent families with IDD children was higher than that of families with both parents alive.

85	Adjustment and Attitude of Parents of Children with Mental Retardation.	Vidhya, R. & Raju, S. (2007).	<i>Journal of the Indian Association of Applied Psychology</i>	To study the level of adjustment and attitude of parents of IDD children.	Parental religion, income, and education do not have any significant influence on adjustment variables, but there is change in parental attitude among different religious groups. Locality of parents' put influences only on the dimensions of social adjustment.
86	Parental stress in raising a child with disabilities in India.	Gupta, V., Mehrotra, P., & Mehrotra, N. (2012).	<i>Disability CBR &amp; Inclusive Development</i>	To determine parenting stress and determinants among parents of children with disabilities in India.	Many parents reported receiving little support from their extended families in taking care of their child. Higher parenting stress in parents of girls raises the possibility of abuse and neglect
87	Psychological distress among parents of children with mental retardation in the United Arab Emirates.	Vivian, K. (2006).	<i>Social Science Medicine</i>	To study the parental stress and psychological distress among parents of children with IDD.	Parents reported more psychiatric symptomatology when the child showed a high level of dysfunction.
88	HEALTH COPING AMONG PARENTS OF CHILDREN AND ADOLESCENTS WITH INTELLECTUAL DISABILITY AND FUNCTIONAL PSYCHOSIS.	Singh, J., & Nizamie, S. H. (2023).	<i>IJCAR</i>	To assess and compare the behaviour problems and health coping strategies among parents of IDD children.	Parents of children and adolescents with functional psychosis reported higher mean that focuses they have better strengthening family life and relationships and the parents' outlook on life with a

					psychologically challenged child as compared to the parents of IDD children.
89	Children with intellectual disability, impact on caregivers: A cross-sectional study.	Bunga, D., Manchala, H., Tondehal, N. R., & Shankar U. (2020).	<i>Indian Journal of Social Psychiatry</i>	To examine the effect of disabilities and nature of parent and child relationships when raising an IDD kid.	The effect of a disability on physical care as well as certain negative emotions increased with the severity of IDD.
90	Depression and anxiety in parents of children with Intellectual Disability IndPsychiatryJ000-6252997172209.	Sharma, R., Singh, H., Murthi, M., Chatterjee, K., & Rakkar, J. (2021).	<i>Industrial Psychiatry Journal</i>	To investigate the psychosocial correlates of anxiety and depression in parents of IDD children.	66.7% of fathers and 94% of mothers of children with IDD experienced symptoms of depression or anxiety, or both.
91	A study on the levels of depression, stress and anxiety of parents having children with intellectual disability.	Merla, S., & Kumar, S. (2021).	<i>The International Journal of Indian Psychology</i>	To look at the anxiety, stress, and depression levels of parents of IDD children.	There was no apparent distinction between the levels of depression, stress, and anxiety experienced by mothers and fathers
92	Perceived Life-stress and Coping: A Comparative Study between Parents with Intellectually Disabled Children and Control.	Majumdar, A., & Chakraborty, A. (2021).	<i>Indian Journal of Health and Wellbeing</i>	To study how parents of IDD children coped with stress.	Parents of IDD children felt more stress in their lives than parents of children without disabilities of any kind.
93	Stress and anxiety in parents of mentally retarded children.	Majumdar, M., Pereira, Y., & Fernandes, J. (2005).	<i>Indian Journal of Psychiatry</i>	To examine stress and anxiety in parent who had children with IDD.	Parents' anxiety levels and stressors were positively correlated.
94	Coping Strategies of Parents for	Upreti, R., & Singh, R. (2017).	<i>International Journal of Basic and Applied</i>	To examine the variations in the kind and degree	Mothers who had completed more education had

	Perceived Stress Resulting from having Intellectually Disabled Child: Comparison Across Educational Level of Parents.		<i>Agricultural Research</i>	of coping mechanisms used by parents of IDD children.	lower misconceptions, better level of awareness of their child's condition, and positive outlook toward their child and child management.
95	Challenges of Parents with Two Intellectually Disabled Children.	Francina, X., Tintu, S., & Ivan, V (2018).	<i>Artha - Journal of Social Sciences</i>	To evaluate psychosocial issues that parents of multiple children with IDD.	Compared with families whose children are typically developing, the challenges faced by the families of two disabled children indicated multiple levels of stress.
96	Stress and Resilience in Parents of Intellectually Disabled Children.	Santhosh, K. R. (2016).	In R. Gopalan (Ed.), <i>Handbook of Research on Diagnosing, Treating, and Managing Intellectual Disabilities</i> (pp. 109-117). IGI Global.	To identify the stressors that could jeopardize the adaptability of parents of children with IDD.	Parents who were older and in the later stages of young adulthood exhibited comparatively higher levels of resilience in comparison to parents who were in the earlier stages of the same period
97	Comparative study of hope and psychological well-being among the parents of physically and intellectually disabled children.	Gull, M. (2015).	<i>International Journal of Modern Social Sciences</i>	To investigate the disparities in psychological health and hope between parents who had physically and intellectually disabled children.	Parents having physically disabled children and those who had children with intellectual disability, differed significantly in terms of their psychological well-being and sense of hope.
98	Psychological and emotional state of parents having	Sekar, N., & Gopalakrishnan, A. (2015).	<i>International Journal on Disability and</i>	To have better understanding of mental as well as emotional health	Parents had considered having their daughter's

	intellectually and developmentally disabled children.		<i>Human Development</i>	of parents of IDD children.	reproductive organs removed and had admitted to hiding their identity in public.
99	Parents of Intellectually Handicapped Children — How they are Told.	Meek, T. (1981).	<i>Australian Child and Family Welfare</i>	To explore the experiences of parents of IDD Children.	Parents frequently had special needs and felt more anxious about their IDD children than those parents who had normal children.
100	Attitude of Parents towards Their Intellectually Disabled Children and its Associated Psychosocial Impact on Them.	Pahantasingh, S., Krishnan, J., Pradhan, J., Samantaray, K., & Pradhan, R. (2018).	<i>International Journal of Health Sciences and Research</i>	To evaluate parents' attitudes toward their IDD children.	There was a significant positive relationship between parents' attitudes and psychosocial impact.
101	Knowledge, attitude, and practice among parents about sex education of their children with intellectual disability.	Ahmad, W., Nazli., & Chavan, Bs. (2022).	<i>Indian Journal of Social Psychiatry</i>	To find out knowledge, attitude, and practice towards sex education among parents having children with IDD.	While parents' income and education levels would greatly increase their children's awareness of sexual education, gender had no bearing on the process of teaching sex education to IDD children.

## Rationale of the Study

It can be extremely upsetting for parents to find out that their child has a diagnosis related to their health, development, learning, or mental health. In “You Are Not Alone”, Patricia McGill Smith wrote, “The day my child was diagnosed as having a disability, I was devastated—and so confused that I remember little else about those first days other than the heartbreak.”

Parenting an MR child (now IDD) is not an easy task (Peshawaria, 1992). Parents having an MR child (IDD) experience a variety of stressors and stress reactions related to the child’s disability ( Orr et al.,

1993 ). Parents of children with IDD are generally affected in many ways. This includes parents who feel sad, depressed, and experience other emotional reactions at various stages of their child's life. Recreational and leisure activities are restricted, which can affect social life. Connections with loved ones, as well as with acquaintances and others, are also impacted. Marital harmony is disturbed for many reasons related to IDD children. The financial burden can also add up. Peshawaria and Menon (1991) stated that having an IDD child in the family means that parents and family members need to adapt to new challenges and circumstances. Some families manage the circumstance better than others. Experience and research have shown that strategies that address the needs of every family member are more successful in assisting the family in coping with the circumstance than strategies that solely address the needs of the IDD child. Understanding and helping parents take care of their family can help them become better at supporting their family's growth, including their own. Studies have also shown that a parent's report of emotional and physical issues increases with the number of unfulfilled needs. (Dunst & Leet, 1987; Dunst, Vance & Cooper, 1986).

Many people have aspirations for their offspring. Although those expectations are not expressed verbally, they nonetheless exist. Their perceptions of their children's potential are diminished when they learn that they have an intellectual handicap. They begin to believe that the dreams they once had would never come true. The question of how family life is affected by intellectual handicap is one that someone has. That is a legitimate cause for worry. The stress levels of parents with IDD children are greater than those of parents with typically developing children. (Hamid, 2021).

In townships, disability is frequently linked to stigma, discrimination, shame, and negativity, which affects how parents perceive it when their child has a disability. Due to uncertainty and a lack of knowledge and understanding about IDD, parents who have recently learnt of their children's condition of IDD, frequently suffer psychological and emotional trauma (Lefakane and Maseko, 2023). Having a child with a disability comes with a number of challenges, such as managing the problematic behaviour of the child, higher medical expenses for treatment, and social stigma. Due to the widespread stigma associated with disabilities in the community, research has shown that kids with disabilities may lack the bravery or not so self-confident to play with kids without disabilities. (Gill and Liamputtong, 2011)

Family recreation, finances, parents' physical and mental health, marital connections, relationships with friends, neighbours, and family members are all aspects of family life that are impacted by an intellectual disabilities. Having a child with an intellectual disabilities poses a number of challenges that directly affect how well parents and families operate. Numerous elements of family life are impacted, including the physical and mental health of all family members, severe stress experienced by all family members, ignorance or neglect of other children's needs, and strained sibling relationships. Kumar & Singh (2012) found significant differences between parents of mentally challenged (now Intellectually and Developmentally Disabled) and normal children. This may be due to the fact that the children affect the psychological life space of parents.

Stress among parents of IDD children was studied by Gupta & Kaur in 2010. The findings indicated that the majority of parents of children with IDD experienced stress; there was a significant



correlation between mental stress and physical stress; differences in gender with regard to stress were seen in the mental domain; and parents reported feeling more mental stress and less physical stress.

Upon discovering that a newborn has an Intellectual and Developmental Disability, parents are naturally upset. Avoidance is prevalent and has an impact on day-to-day living. A parent's hopes and expectations for their child must often be drastically altered when they learn that their child has an Intellectual and Developmental Disability, which is often not diagnosed until after the child turns one year old. They frequently struggle with protracted sadness, rage, guilt, and an inability to handle significant practical and financial issues. Some parents choose to ignore their kids, while others become overly preoccupied with raising them, neglecting other crucial facets of family life. Having a child with an Intellectual and Developmental Disability is always challenging for the parents. It has a negative inverse effect on their lives (Abdul Hamid, 2021).

Service providers would be able to give each family member with the proper support services if they had an understanding of how the nature of needs of parents of children with IDD vary over time. For a while, a child with IDD generates additional needs. A need is anything that is wanted or absent but that is needed to fulfil a purpose or arrive at a particular result. When a child is identified as having a disability, parenting is impacted, and future expectations about the child and the future may need to be revised. According to Peshawaria & Menon (1991), the most important requirements for parents who have an IDD child, are parental and familial adaptations, information on government benefits, communication of diagnosis, the future of the child, accessibility to formal as well as informal support, and parent training programmes. According to a research by Haldy (1990), mothers' satisfaction with the assistance they received from family members in caring for their child was positively correlated with their feelings of competence. Adequate social support was also found to have a positive impact on mothers' feelings of competence regarding their ability to raise children. When their children were classified as having milder mental retardation, mothers expressed higher levels of satisfaction with the guidance and services provided by different professionals.

According to a survey of seven kinds of needs conducted by Bailey, Blasco, and Simension (1992), the most common needs were for information, specific financial assistance, and the chance to connect with other parents. Mothers reported to have significantly greater needs than fathers in the areas of child care, communication with others, and support from family and friends. According to studies, parents were more likely to report that they lacked the time, energy, or personal commitment necessary to carry out the intervention that was recommended for their child if they had more needs unrelated to child-level interventions (Dunst and Leet, 1987; Dunst, Vance and Cooper, 1986). According to Boon (1990), the main concerns expressed by parents, who had mentally retarded (now intellectually and developmentally disabled) children, were high care requirements, communication skills of the child, self-help training, transportation/service access, and respite care. According to Whitehead (1990), the most frequently mentioned needs by parents were for information on how to teach the child, assistance in finding respite care, more time for oneself, information about future services, community resources that were available, and information about prognosis and diagnosis.

Parents indicated a need for information in Gowen's (1993) study on how to manage the time and emotional demands of parenting, find community resources, plan for their child's future, and comprehend their child's legal rights. According to Peshawaria's (1988) analysis of service demand, the most significant needs identified by parents for which they wanted were training in self-help, behaviour problem management, and communication. Peshawaria et al. (1998) discovered that there were gender disparities in enabling and impeding elements that impact the abilities to cope for parents of children with IDD in India. There is increased pressure on mothers to manage household duties and paid time off for child care.

One of the major concerns of parents of Intellectually and Developmentally Disabled (IDD) children is how their child will be taken care of when they die. They feel that no one else treat them with such a love and care, even they are scared have about how their child will be able to manage to survive in the world. Sometimes they try to acquire wealth for children but that does not take them out of worry regarding the future of child.

Apart from a number of unforeseen issues, Intellectual and Developmental Disabilities have caused significant problems across the globe because of their intricate social, medical, psychological, legal, and educational components. At all societal levels, it is regarded as one of the most challenging issues to comprehend, characterize, teach, and resolve to everyone's satisfaction. Recently, there has been an increase in parents who have IDD child and researches have become increasingly diverse in nature. A significant number of studies on the parents having IDD children have been published in recent years, and many of them contain insightful data. The problem of IDD has engaged the attention of parents, teachers, professionals, NGOs and psychologists in both India and abroad.

### **Knowledge gap**

The researcher conducted a thorough review of related literatures in abroad and in India related to parents' knowledge, problems and needs for having an IDD child. Despite a thorough review of the literature, the present researcher was unable to locate any adequate studies in West Bengal that have examined the needs, problems, and knowledge of parents raising an IDD child. The researcher, thus, discovered a knowledge gap in the above mentioned research area and formulated her current research title.

### **Statement of Problem**

Keeping the above discussion in mind, the researcher has conducted her current study under the title: *Parents of Intellectually and Developmentally Disabled Children: Their Knowledge, Problems and Needs*

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## **Operational Definitions of the Key Terns Used**

- 1. Parents:** A person's father or mother.
- 2. Disability:** Limitation or inability to carry out a task within the parameters or in the way that is thought to be typical for a human being.
- 3. Intellectual and Developmental Disability (IDD):** Severe and chronic disability that leads to notable deficits in intellectual functioning (thinking, learning, problem solving) as well as in adaptive skills.
- 4. Intellectually and Developmentally Disabled Children:** Children having notable deficits in intellectual functioning as well in adaptive skills.
- 5. Knowledge:** Knowledge, which can be acquired via experience, education, perception, discovery, or learning, is the familiarity, awareness, or understanding of someone or something, including facts, information, descriptions, or skills.
- 6. Problem:** Something that causes difficulty or that is hard to deal with
- 7. Need:** Something that is required as essential in life.
- 8. Gender:** Either of the two sexes (male and female)

## **Research Questions:**

The present study has been carried out with the following Research Questions:

1. Do Parents have enough knowledge about Intellectual and Developmental Disability (IDD)?
2. What are the problems faced by the parents of IDD children?
3. What are the needs of parents of IDD children?

## **Objectives of the Study**

### **1. To Study the knowledge of parents about intellectual and developmental disability (IDD)**

- 1.1. To Study the knowledge of parents about IDD on the basis of their gender
- 1.2. To Study the knowledge of parents about IDD on the basis of their age
- 1.3. To Study the knowledge of parents about IDD on the basis of their education
- 1.4. To Study the knowledge of parents about IDD on the basis of their occupation
- 1.5. To Study the knowledge of parents about IDD on the basis of their residential background
- 1.6. To study the knowledge of parents on the basis of early intervention therapy provided to their IDD children

## **2. To investigate the problems faced by the parents of IDD Children**

- 2.1.** To investigate the problems faced by the parents on the basis of their gender
- 2.2.** To investigate the problems faced by the parents on the basis of the level of disability of their children
- 2.3.** To investigate the problems faced by the parents on the basis of their income
- 2.4.** To investigate the problems faced by the parents on the basis of their residential background
- 2.4.** To investigate the problems faced by the parents on the basis of the type of their family
- 2.5.** To investigate the problems faced by the parents on the basis of the type of schooling of their IDD children
- 2.6.** To investigate the problems faced by the parents on the basis of the gender of their differently abled child

## **3. To study the needs of parents of IDD Children**

- 3.1.** To study the needs of parents of IDD children on the basis of the gender of their differently abled child.
- 3.2.** To study the needs of parents of IDD children on the basis of the level of their child's disability
- 3.3.** To study the needs of parents on the basis of their income
- 3.4.** To study the needs of parents on the basis of their residential background
- 3.5.** To study the needs of parents of IDD children on the basis of early intervention therapy provided to their child
- 3.6.** To study the needs of parents on the basis of their availability of training about management of their child

## **Hypotheses**

- H<sub>01</sub>.** There will be no significant mean difference in knowledge of parents about IDD on the basis of their gender
- H<sub>02</sub>.** There will be no significant mean difference in knowledge of parents about IDD on the basis of their age
- H<sub>03</sub>.** There will be no significant mean difference in knowledge of parents about IDD on the basis of their education
- H<sub>04</sub>.** There will be no significant mean difference in knowledge of parents about IDD on the basis of their occupation
- H<sub>05</sub>.** There will be no significant mean difference in knowledge of parents about IDD on the basis of their residential background
- H<sub>06</sub>.** There will be no significant mean difference in knowledge of parents on the basis of early intervention therapy provided to their IDD children
- H<sub>07</sub>.** There will be no significant mean difference in problems faced by the parents on the basis of their gender.
- H<sub>08</sub>.** There will be no significant mean difference in problems faced by the parents on the basis of the level of disability of their children

- H<sub>09</sub>.** There will be no significant mean difference in problems faced by the parents on the basis of their income
- H<sub>010</sub>.** There will be no significant mean difference in problems faced by the parents on the basis of their residential background
- H<sub>011</sub>.** There will be no significant mean difference in problems faced by the parents on the basis of the type of their family
- H<sub>012</sub>.** There will be no significant mean difference in problems faced by the parents on the basis of the type of schooling of their IDD children
- H<sub>013</sub>.** There will be no significant mean difference in needs of parents on the basis of the gender of their differently abled child.
- H<sub>014</sub>.** There will be no significant mean difference in needs of parents on the basis of the level of disability of their children.
- H<sub>015</sub>.** There will be no significant mean difference in needs of parents on the basis of their income
- H<sub>016</sub>.** There will be no significant mean difference in needs of parents on the basis of their residential background
- H<sub>017</sub>.** There will be no significant mean difference in needs of parents on the basis of early intervention therapy provided to their IDD children
- H<sub>018</sub>.** There will be no significant mean difference in needs of parents on the basis of the availability of training about management of their child.

#### **Delimitations of the Study:**

- The present study was delimited to the 200 parents who have children with Intellectual and Developmental Disabilities (IDD) admitted to special schools and mainstream schools.
- The samples were selected from Kolkata and surroundings in West Bengal.
- Sample selection was done by using purposive sampling.

## CHAPTER - 3

### RESEARCH METHODOLOGY

**Research Design:** For the present study the researcher has applied Mixed Method Research Design.

**Research Method:** The researcher used Descriptive Research Method for her study. For quantitative data collection she used Survey method, and for qualitative data collection the researcher used Case Study method.

**Population and Sample:** The researcher selected West Bengal as the population of her study. For the present study a sample of 200 parents of children with Intellectual and Developmental Disability admitted to special schools and mainstream school in Kolkata and surroundings were selected out of the total population with the help of purposive sampling technique.

**Tools and Techniques:** In order to collect relevant data for the fulfilment of the proposed objectives, the following tools were employed by the researcher:

For Survey, the researcher used three questionnaires:

**i. Knowledge Questionnaire- (Adopted from Panigrahi and Nanda):** The questionnaire was developed by Panigrahi and Nanda in 2014. 25 Items were taken from the GEM Questionnaire developed by NIMH Secundrabad. Zero (0) was given for every wrong responses and One (1) for every correct responses. Higher the score more the knowledge. The questionnaire has three sections: Section I consisted of 12 questions to measure knowledge about general information regarding disability. Section II consisted of 9 questions related to causes of disability and Section III contained 4 questions on management of students with special need.

**ii. Parents Problem Inventory (PPI)- (Adopted from Dr. Anju Singh):** Parents Problem Inventory was designed by Dr. Anju Singh to assess the problems of mothers and fathers having children with Intellectual and Developmental Disabilities. The PPI tool consists general information about family background information and 57 items were distributed over nine (9) problems areas. They were family problems, psychological problems, physical problems, social problems, school and vocational problems, profession advice problems, child management problems, financial problems and psychosomatic problems. In each area the number of items varied from 3-10.

**iii. Family Need Schedule (Parents)- (Adopted from Reeta Peshawaria, 1994):** The tool was developed by Peshawaria, Menon, Ganguly, Roy, Pillay and Gupta in 1995. NIMH- FAMNS is a semi structured interview schedule. The schedule contains 45 items organised into 15 categories or areas, including information-condition, child management, facilitating interaction, services, vocational planning, sexuality, marriage, hostel, personal-emotional support, personal-social support, physical support, financial security, family relationships, future planning and Govt benefits.

For Case Study, the researcher used Semi-structured Interview schedule.

**Procedure for Data collection:** The researcher collected quantitative and qualitative data concurrently to have a better understating of the findings of her study, analysed the two data sets separately and mixed the two databases by merging the results during data analysis and interpretation. Quantitative data were obtained through three questionnaires. Written consent was taken from the school authority to conduct the survey through questionnaires filled by the parents of IDD children admitted to their schools. Parents were briefed about the nature of the study and then consent was taken from them to collect the data. The questionnaires were made both in English and Bengali language as the majority of the state speaks in Bengali. After getting back the filled questionnaires the responses were scored according to the scoring procedure.

Qualitative data were obtained through interview to have a better understanding of the study. Participants were informed of the study through the school authorities. After the initial contacts were made, interviews were taken from those parents who gave consent for the same. Permission was taken from parents to use a voice recorder during their interviews. Adequate rapport with the parents of IDD children. During the interviews, parents were requested to give a detailed description of their experiences of having IDD child. All the interviews were conducted in Bengali Language, recorded with mobile voice recorder and lasted for 20-30 minutes.

## CHAPTER - 4

### DATA ANALYSIS AND INTERPRETATION

The quantitative data were analysed by using SPSS. Descriptive Statistics like Mean and Standard Deviation; and inferential statistics like t-test, ANOVA and Pearson Coefficient Correlation were used to analyse the data. The qualitative data were analysed by Thematic analysis.

#### Summary of the Inferences

No of Hypotheses	Hypotheses	Inference
H <sub>01</sub>	There will be no significant mean difference in knowledge of parents about IDD on the basis of their gender	Accepted
H <sub>02</sub>	There will be no significant mean difference in knowledge of parents about IDD on the basis of their age	Rejected
H <sub>03</sub>	There will be no significant mean difference in knowledge of parents about IDD on the basis of their education	Rejected
H <sub>04</sub>	There will be no significant mean difference in knowledge of parents about IDD on the basis of their occupation.	Rejected
H <sub>05</sub>	There will be no significant mean difference in knowledge of parents about IDD on the basis of their residential background.	Rejected
H <sub>06</sub>	There will be no significant mean difference in knowledge of parents on the basis of early intervention therapy provided to their IDD children.	Rejected
H <sub>07</sub>	There will be no significant mean difference in problems faced by the parents on the basis of their gender.	Accepted
H <sub>08</sub>	There will be no significant mean difference in problems faced by the parents on the basis of the level of disability of their children	Rejected
H <sub>09</sub>	There will be no significant mean difference in problems faced by the parents on the basis of their income	Rejected
H <sub>010</sub>	There will be no significant mean difference in problems faced by the parents on the basis of their residential background	Accepted
H <sub>011</sub>	There will be no significant mean difference in problems faced by the parents on the basis of the type of their family.	Rejected
H <sub>012</sub>	There will be no significant mean difference in problems faced by the parents on the basis of the type of schooling of their IDD children	Rejected



<b>H<sub>013</sub></b>	There will be no significant mean difference in problems faced by the parents on the basis of the gender of their disabled child.	Accepted
<b>H<sub>014</sub></b>	There will be no significant mean difference in needs of parents on the basis of the level of the disability of their children.	Accepted
<b>H<sub>015</sub></b>	There will be no significant mean difference in needs of parents on the basis of their income.	Rejected
<b>H<sub>016</sub></b>	There will be no significant mean difference in needs of parents on the basis of their residential background	Rejected
<b>H<sub>017</sub></b>	There will be no significant mean difference in needs of parents on the basis of early intervention therapy provided to their IDD children.	Rejected
<b>H<sub>018</sub></b>	There will be no significant mean difference in needs of parents on the basis of the availability of training about management of their child.	Rejected

#### **Themes and sub-Themes Emerged from Case Studies**

<b>Themes</b>	<b>Sub-themes</b>
Emotional Reactions	Sadness
	Worry about future
	Stress
Social Reactions	Stigma
	Isolation
Knowledge about the Condition	Personal Knowledge
	Medical Diagnosis
	Teacher Information
Cause of the Condition	Spiritual Beliefs
	Medical
Caregiving Challenges	Management of the child
	Safety Issues
	Employment and financial issue
Needs to raise IDD child	Support Services and financial help
	Govt benefits

## CHAPTER - 5

### FINDINGS AND DISCUSSION

#### ◦ **Findings related to the knowledge of parents of IDD children about Intellectual and Developmental Disabilities:**

1. From the statistical analysis, it was found that there was no significant mean difference in knowledge about Intellectual and Developmental Disabilities between mothers and fathers of IDD children.
2. There were significant mean differences in knowledge among parents of IDD children about Intellectual and Developmental Disabilities on the basis of their age. The parents in the age group of 35-44 possessed more knowledge than the parents of 25-34 and 45-54 age group.
3. It was noticeable that parent's education had a high impact on knowledge of parents about IDD. Parents who completed their Undergraduate degree possessed more knowledge than those who completed their education upto 9-12th or upto 8th standard.
4. The study revealed that parent's occupation had a high impact on the knowledge of parents about IDD. Parents who were employed in Govt. sectors showed higher level of knowledge than parents working in private sectors or parents who were housewives.
5. The study concluded that there was a significant mean difference in knowledge of parents about IDD on the basis of their residential background. The parents who resided in urban area had a better knowledge than parents residing in rural areas of West Bengal.
6. The study observed significant mean difference in knowledge of parents about IDD on the basis of the early intervention therapy provided to their IDD children. Parents whose child got any kind of early intervention therapy showed higher level of knowledge than those whose child did not get any kind of intervention therapies.

#### ◦ **Findings related to the problems of parents having IDD children:**

1. It was observed that the mean difference in problems faced by the parents of IDD children on the basis of their gender was not statistically significant.
2. There was a significant mean difference in problems faced by the parents on the basis of the level of disability of their IDD children. The parents who have moderate IDD child faced greater problems than those having mild IDD child.
3. The study concluded that the mean difference in problems faced by the parents having IDD child on the basis of their income were statistically significant. The parents who earn below Rs. 10,000/- faced more problems than the parents who earn Rs. 10,000/- and above.

4. It was found that there was no significant mean difference in problems faced by the parents on the basis of their residential background.
5. There was a significant mean difference in problems faced by the parents on the basis of the type of their family. The parents who belonged to the non nuclear family faced much greater problems than nuclear family.
6. There was a statistically significant mean difference in problems faced by the parents on the basis of the type of schooling of their IDD children. The parents whose IDD child is admitted to regular schools faced much greater problems than those admitted to special schools.
7. There was no significant mean difference in problems faced by the parents on the basis of the gender of their disabled child.

◦ **Findings related to the needs of parents having IDD children:**

1. It was concluded that there was no significant mean difference in needs of parents on the basis of the level of disability of their IDD children.
2. There was a significant mean difference in needs of parents having IDD child on the basis of their income. The study revealed that the parents who earn below Rs. 10,000/- expressed greater needs than the parents who earn Rs. 10,000/- and above.
3. There was a significant mean difference in needs of parents on the basis of their residential background. The parents who reside in the non urban area expressed greater needs than those who reside in the urban areas.
4. There were significant mean differences in parental needs on the basis of early intervention therapy provided to their IDD children. The parents whose IDD child did not get any early intervention therapy expressed greater needs than those whose IDD child got the early intervention therapy.
5. It was noticed that parents who received training on how to manage their child had different needs compared to those who did not receive training. The parents who did not get any training about management of their IDD child expressed greater needs than those who did a training course about management of their IDD child.

◦ **Findings related to correlation among knowledge, problems and needs of parents having IDD children:**

1. In this study there was a significant negative correlation found between knowledge and problems of parents of IDD children.
2. There was a positive correlation between problems and needs of parents of IDD children.

3. There was a significant negative correlation between knowledge and needs of parents of IDD child.

## **Discussion**

The researcher concluded that gender did not have any effect on the knowledge of parents of IDD children regarding IDD. Similar to this conclusion. Similar to this result, the result of a study conducted by Purty and Singh (2018) clearly indicated that there were no differences found among mothers, fathers and other caregivers who were part of the study. Regarding the misunderstanding of the etiology, general knowledge, and management concerning IDD children, they all had somehow the same understanding.

There were significant mean differences in knowledge among parents of IDD children about Intellectual and Developmental Disabilities on the basis of their age. The researcher found that parent's education and occupation had a high impact on the knowledge of parents about IDD. In a similar vein, Bency et al. (2017) discovered that mothers belonged to higher occupational status showed higher knowledge than mothers with lower occupational status, and that this association was statistically significant. Mothers who completed more education had a higher degree of knowledge, and the difference was statistically significant.

Purty and Singh (2018) also discovered that caregivers with less education than matriculation exhibited greater misconceptions about the etiology, general information, and management of IDD children when compared to caregivers with matriculation-level education or above.

Parents who resided in urban area had a better knowledge about Intellectual and Developmental Disabilities than parents residing in rural areas of West Bengal. Similarly it was found in the study by Purty and Singh (2018) that the caregivers from rural areas were more likely to be misinformed about the causes and contributing factors of intellectual disability. On the other hand, there was no apparent distinction in the general information area between caregivers who worked in rural and urban areas .

The finding of the current study is also supported by the study conducted by Shetty and Menezes (2013) in which it was found that 50% parents who resided in rural areas believed that it is the evil eye that has caused their child to develop this condition. They also mentioned that uneducated parents of ID had not possessed any knowledge of Intellectual Disability.

A growing proportion of children are being diagnosed with IDD. Increasing awareness of this disability and ensuring that the affected family accepts the diagnosis are being supported by educational, cultural as well as the social facets of society. Not all parents of IDD children have adequate knowledge regarding IDD. It was found in a study conducted by Vijayarani, Balamurgan and Kasthuri (2016) that 11.8 was the average knowledge score, while 39.33% was the average percentage. Those parents or caregivers (39.33%) indicated a lack of understanding. Only 2% parents had complete knowledge compared to the majority of 78% who had had inadequate knowledge and 20% who had somewhat adequate knowledge

The present study observed that the mean difference in problems of parents of IDD children on the basis of their gender was not statistically significant. Similarly in Rajan and Mondal's study (2015) there was no difference relationship domain (29.5% vs 30.1%; $p=0.56$ ) in between the parents. In terms of career, sibling influence, physical care, health, and particular thought domain, mothers faced greater challenges than fathers. In terms of support, finances, social interaction, and shame/ridicule, fathers face greater difficulties.

But in contrary to these findings, Malekshahi et al. (2020) found that psychosocial difficulties affected all parents; however, mothers experienced greater difficulties on average because of their distinct roles within the family.

As per the results of this study, parents faced significantly different problems depending on the level of disability of their IDD children, income, type of the family of parents and type of schooling of their IDD child. Likewise, in the findings of a research conducted by Fadakar Sogheh and others, it was found that over 50% of the families with differently abled children had trouble identifying their problems. The seriousness of these issues had important consequences. A significant association was there among the gender of the child, the income of the family, and the level of their disability.

Parents who earn below Rs. 10,000/- faced more problems than the parents who earn Rs. 10,000/- and above. Likewise, Abasi et al. (2010) discovered that having adequate financial resources is essential for the mental well-being of parents.

Parents have a profound and significant influence on how well their child grows and develops in a variety of domains. If a child has a disability, this influence is amplified because the child is more dependent on his parents for longer periods of time, which leads to issues that call for special needs.

Findings of the present research revealed that no significant mean differences were found in needs of parents on the basis of the disability level of their IDD children. Similarly, findings of a study by Noman and Yasir (2022) demonstrated that there were notable variations in parents' material, social, emotional, and cognitive needs based on the level of disability of their child.

Parents of children with IDD showed a significant mean difference in their needs on the basis of their income. The parents who earn below Rs. 10,000/- expressed greater needs than the parents who earn Rs. 10,000/- and above. In contrary to this, findings of the study by Noman and Yasir (2022) demonstrated that parents' cognitive, material, social, and emotional needs were not significantly different based on their financial situation.

Parents of IDD children have more problems when they know less about the disabilities. The results match up with other studies that show parents with higher levels of education are better able to adapt to their child's disability.

Similarly, according to Davys, Mitchell and Haigh (2014) children's level of functioning is limited by families' ignorance of IDD. In support, the study of Davys, Mitchell and Haigh discovered that Families w

ith children with IDD faced difficulties in making plans for the special care of their children due to a lack of knowledge about IDD.

Another study by Hjemdal (2007) reported that educated parents experienced greater resilience than others. The researcher also identified education and having a better knowledge as a protective factor of resilience and better child management. Having a better knowledge and awareness about the condition of the child helps a person to find out the possibilities of how to deal with the problems and managing the IDD child. When parents increase their knowledge, they will be able to accept their child's condition as a fact and at times, they do discover paths, use them, and become more adept at facing those difficulties and experience more peace.

## **Conclusion**

The outcomes of the present research contribute to the knowledge in the area of parents' awareness, knowledge, problems and needs for having IDD children. This study offers more evidence-based policy recommendations for government agencies to consider when developing policies regarding the support that families of children with IDD require. Additionally, better systems and programs for professional support must be planned and implemented in order to greatly improve the quality of life for families raising IDD children. More generally, it is crucial on a number of pragmatic levels to assist families in addressing the difficulties posed by caring for children with IDD. So, professionals should have ongoing conversations with the families of these IDD children when offering services to them.

It is important to never forget how parents' dreams about their lives would change after welcoming their first child, who seems to be everything to them, but is diagnosed with a disability. The changed dynamics at home, including the decision of parents to give their disabled child more attention, have also been known to have an impact on that disabled child's relationships with other siblings. These situations are inherently stressful and deeply upsetting for parents, who find it difficult to balance their already limited time and energy between providing for their children's (CWSN) basic needs—such as regular medical care and rehabilitation, and their own. Helping parents gain a basic understanding of their disabled child's problems and educational needs can result in a more positive attitude about their effectiveness as parents, which increases the child's chances of making a satisfactory adjustment at home. The realisation that they are not alone, and that the disability in the family, as well as the family's reaction to it, is shared by others, will encourage the parents to adopt a more positive attitude. It is critical that parents properly explain their child's condition to others in order to help people develop positive opinions and attitudes toward intellectually disabled people. Parents can only do this if they are fully aware of their child's condition and accept their child as it is. Service providers, NGOs, Govt. would be able to give each family member with the proper support services if they had an understanding of how the needs of parents of IDD children vary time to time.

## **Scope of Further Studies**

Though there were many limitations, the current research produced some significant findings which can contribute to the research knowledge base in the area of parents' awareness, knowledge, problems and needs for having IDD children. The researcher recommends the following investigations:

1. Majority of studies on parenting problems, family burden and needs associated with raising a disabled child have focused on mothers. Further research can be conducted on fathers of IDD children and their problems.
2. In depth Case Studies can be done on the real life journey of mothers having girl child with IDD.
3. Qualitative research can be done on the parents dealing with the sexual problems of Children having IDD.
4. Further research can be done on the perspectives of school teachers and parents on the health and hygiene needs of IDD children.

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