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

The Thesis Submitted to the Department of Education,
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Dedicated

to

Maa

Late Smt. Jayanti Rooj

Certified that the Thesis entitled

"PARENTS OF INTELLECTUALLY AND DEVELOPMENTALLY DISABLED CHILDREN: THEIR KNOWLEDGE, PROBLEMS AND NEEDS" submitted by me for the award of the Degree of Doctor of Philosophy in Arts at Jadavpur University, Kolkata is based upon my work carried out under the supervision of Professor Bishnupada Nanda, Department of Education, Jadavpur University and neither this thesis nor any part of it has been submitted before for any degree or diploma anywhere/elsewhere.

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LIST OF ABBREVIATIONS

IDD	-	Intellectual and Developmental Disabilities
ICF	-	International Classification of Functioning, Disability and Health
WHO	-	World Health Organisation
MR	-	Mental Retardation
PWD	-	Persons with Disabilities
PWD Act	-	Persons with Disabilities Act
RPWD Act	-	Rights of Persons with Disabilities Act
NGOs	-	Non-Governmental Organisations
AAMR	-	American Association on Mental Retardation
AAIDD	-	American Association on Intellectual and Developmental Disabilities
DSM-5	-	The Diagnostic and Statistical Manual of Mental Disorders - 5
IQ	-	Intelligence Quotient
ADHD	-	Attention Deficit Hyperactivity Disorder
ASD	-	Autism Spectrum Disorder
CP	-	Cerebral Palsy
PPI	-	Parents Problem Inventory
NIMH-FAMNS	-	National Institute for the Mentally Handicapped - Family Needs Schedule
CWSN	-	Children with Special Needs
ANOVA	-	Analysis of Variance

CHAPTER - I

INTRODUCTION

1.1. Concept of Disability

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).

The words “disability”, “impairment” and “handicap” are frequently used in literature related to health, education, and counselling. In order to encourage appropriate use of these words, WHO provided the following definitions in their 1980 manual named “International Classification of Impairment, Disability, and Handicap”:

Impairment – Loss or abnormalities in a person's physiological, psychological, or anatomical structure or function is considered an impairment.

Disability – Disability is defined as any 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.

Handicap – A person with a disability who is unable to perform a regular role in life, is said to be handicapped.

Approximately 200 million of 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.

1.2. Historical Perspectives of Intellectual and Developmental Disabilities

1.2.1. Historical Perspectives of Intellectual and Developmental Disabilities: Western Countries

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," "feebleminded," 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”. Ancient Greek and Roman people saw individuals with Intellectual and Developmental Disabilities as a burden to the society. They were therefore treated awfully. The Greeks and Romans often killed infants who were considered as malformed. Even some of them were put up for sale as entertainment. People use to believe that they were the victims of either God's rage or any demonic influence. Thus individuals with IDD were thought to be less than a human being.

Conditions of IDD (Earlier MR or Mental Retardation) were mentioned in the works of the Greeks (1552 BC) and the Romans (449 BC) (Barr, 1913; Lindman and McIntyre, 1961). In their official documents, they included words like "fools," "monsters," and so forth. The civilization in Sparta and Athens conducted infanticide in order to rid their cities of deformities and defects because they saw individuals with IDD as non-humans and hence treated them as such. Romans raised fools and clowns as entertainment. According to Kanner (1964), many wealthy families kept these Intellectually and Developmentally Disabled persons for the entertainment of their family members and guests while achieving grandeur and fame. Many disabled persons ended themselves in chains, cages, or under death sentences, or they were abandoned to wander and care for themselves.

Discrimination against individuals with disabilities had existed throughout the history across so many civilizations. People with Intellectual and Developmental Disabilities, according to Wolfensberger, had allegedly been referred to in a variety of ways throughout the prolonged history of Western culture as "less than human," "a burden upon society," "a menace to society," "sick," "mentally ill," "objects of pity," "eternal children," and "holy innocents." It was during middle to late 19th century that an increasingly accepting mentality towards people with IDD started to grow in favour of them. Approximately during this time, services and institutions for IDD people began to appear.

Whitney (1954) and Davies (1959), in their writings, stated that there were several superstitions in the early history of Mental Retardation (now Intellectual and Developmental Disabilities). Christian institutions offered compassion and care to these “fools” and “idiots” at least 200 years after the death of Jesus Christ, when Roman Catholic Churches first began to recognise these “retarded” (now Intellectually and Developmentally Disabled) people as human beings and therefore they began to show their responsibilities. Thus, Christianity provided the first real hope for those who were less fortunate. According to Kanner (1964), St. Nicholas Thaumaturges, the Bishop and Wonder Worker, advocated for providing care and protection for those with weak minds in the fourth century AD.

Roman Catholic churches in Europe started offering asylums to the “feeble-minded” (Intellectually and Developmentally Disabled) people in the thirteenth century (Kott, 1971). The most well-known asylum for such individuals was the Bicetre of Paris, founded by St. Vincent de Paul and his Sisters of Charity, although those institutions were not intended for the treatment or education of the

Intellectually and Developmentally Disabled people. However, throughout that same time, Protestant churches had the belief that those people were "filled with Satan" and "possessed by the devil," and that their peculiar behaviours had a religious connotation. The end result was that, with very few exceptions, Intellectually and Developmentally Disabled people were treated with mockery, persecution, and even obliteration. They were "tortured, tormented, and punished in an attempt to exercise the demons within." When they were treated more humanely, it was usually because of some false beliefs about having a unique "connection" with God. A community that could only see such disparities through the tunnel-vision of superstition did not appear to consider the possibility that they might be worthy people, capable of some learning, and with inherent rights as citizens. (Gearheart, 1980, p. 249)

Several influential figures, including Itard, Esquirol, Guggenbuhl, Howe, and Seguin, contributed significantly to the development of the concept of education and care for individuals with Intellectual and Developmental Disabilities. This was developed with the perspective that IDD people could be taught. The most significant of them was arguably French doctor Jean-Marc Itard, who was renowned for his treatment with Victor, the Aveyron wild boy. Itard (1774–1838), who tried to teach cognitively impaired Victor, was considered the founder of systematic instruction for children with IDD. Victor was discovered in France's Caune Woods, bare and unable to speak. After five years of Itard's efforts to teach Victor to read and talk, Victor was able to comprehend some written words.

One of the most important developments in the history of IDD was the Eugenics movement in the late nineteenth century. The Greek terms for "good" and "origin," or "good birth," are where the word "Eugenics" originated. This social philosophy promoted increased rates of sexual reproduction for individuals with desired traits (positive Eugenics), lower rates of sexual reproduction and sterilisation for individuals with less desirable or undesired traits (negative Eugenics), or both (Osborn & Frederick, 1937). The goal is to improve human genetic traits. Francis Galton, whose studies on the intelligence of the British upper class led him to believe that desirable characteristics could be passed down through generations, coined the term "Eugenics" in the late 1800s. He discovered that their desirable characteristics, like great intelligence, are inherited and carried down the generations. As a result, he was in favour of selective breeding, which holds that humankind could be improved by encouraging those who are physically fittest to procreate (Norrgard, 2008). The notion became widely accepted in America in the early twentieth century, and it resulted in a negative view of individuals with disabilities, especially those who were mentally ill and intellectually or mentally week, because they were thought to be contaminating the country's gene pool.

Custodial institutions became more popular at the end of the nineteenth and the beginning of the twentieth centuries, despite the fact that institutional care continued after the period of Itard. Mental hospital was an example of that. for example. In terms of providing care for people with intellectual and developmental disabilities, it achieved great improvements. Economically, many nations at this time were struggling, and social conditions were frequently severe. This had an effect on educating people with intellectual disabilities as well as reinforcing fear and stereotypes among the general public. Education was often utilised in custodial institution only to keep the institution functioning rather than imparting to the individuals new skills that would enable them to lead productive lives out of it in society. Thus, individuals with Intellectuals and Developmental Disabilities were becoming more socially isolated.

This type of treatment was still given until Dr. Wolfensberger came up with his seminal work in the middle of the twentieth century. Education and care for individuals with intellectual and developmental disabilities had changed significantly. Dr. Wolfensberger generated the "Principle of Normalization," which attempted to improve the lives of people who had developmental and intellectual disabilities. A panel of 178 experts rated Wolfensberger's 1972 book, “The Principle of Normalization in Human Services”, as the most influencing publication in the domain of Intellectual and developmental Disabilities since 1966. Dr. Wolfensberger vigorously fought against propensity of society to marginalise and devalue individuals with IDD and advocated for the worth of their lives. Also, he was the primary developer and exponent of citizen advocacy and social role valorisation. In order to recognise the importance of a vulnerable person, this was centred on people speaking up and standing up for those who are more vulnerable in society.

Enhancing the living conditions of those with Intellectual and Developmental Disabilities was one cause for advocacy. This includes putting a stop to segregated living in institutions and other places. This has changed gradually, and many nations still have difficulty offering meaningful and equitable services of high calibre to those with Intellectual and Developmental Disabilities. The above initiatives increased the accessibility of social and health services for people with IDD, improving their overall health and wellness. Individuals who are Intellectually and Developmentally Disabled, now tend to live longer than they did a decade ago or so.

According to Chavan and Rozatkar (2014), the history of Intellectual and developmental Disabilities (IDD) has gone through a number of extremely difficult eras:

I. Pre-Industrialization Phase: From the earliest days of civilization until the beginning of the industrial era, people with "abnormal" physiognomy were viewed with fear or mockery (and maybe still are in many societies).

II. Industrialisation Phase: Although the industrial revolution is linked to rising income and productivity, it also had a number of negative repercussions. Slums, poverty, diseases, and criminal activity all developed as a result of migration to larger cities. Families started to value members who could work and started to ignore those who couldn't. The person with low IQ was excluded and given the demeaning and stigmatising labels of feeble-mindedness.

III. Humanitarian Approach: Dr. Samuel Gridley Howe, a physician from Boston, urged the Massachusetts Legislature to establish a commission to investigate the situation of those "idiots" in 1846. Following a thorough examination, he made the first observation that "These are the suitable topics of education, they can be trained to do some type of labour and they can be made self-sufficient." As a result, numerous state-run schools were established for these individuals. Despite their success, these schools failed because Howe and his associates, Wilbur and Sequin, had unrealistic and unrealistic hopes that they might make all "idiots" behave normally.

IV. The Defectives' Demonology: Directly or indirectly, scientific advancements such as Darwinism, sociological theory, Mendelian genetics, and Binet psychometric testing maintained that people with weak minds who could be easily detected and measured posed a danger to society as a whole. As a result, society began to consider ways to prevent feeble mindedness from happening and to regulate individuals who already had it. The segregation strategy appeared to be the most effective way to provide sensible and economical care for the mentally handicapped (Intellectually and Developmentally Disabled) while also promoting preventative and social safety.

V. John F. Kennedy and his Period: In 1963, JF Kennedy addressed the US Congress and requested additional funding to meet the needs of those who have mental retardation based on the President's Commission on Mental Retardation (IDD). Consequently, almost all states began to offer these people particular educational programmes.

1.2.2. Historical Perspectives of Intellectual and Developmental Disabilities in India

Throughout history, even during the reigns of Muslim kings, and almost up until the start of colonial authority in India, the rulers have served as examples of guardians by constructing charitable homes that provide food, clothing, and care for the poor and differently abled persons. Despite its charitable basis, the community, which was governed by locally elected bodies under the Panchayati system at the time, collected enough information on individuals with disabilities to enable provisions of service. Changes in the type of care and management provided to those with Western influences became apparent with the beginning of colonial administration in India.

With the urban lifestyle, views towards differently abled persons also changed. In particular for families who had moved into cities, the administrative authorities started to demonstrate interest in offering a formal education system for people with disabilities. The transition of individuals having Intellectual and Developmental Disabilities from "community inclusive settings," where families provided assistance, to "asylums," managed by state or non-governmental organisations, resulted in changes in the way of life for these individuals (Chennai, then Madras, Lunatic Asylum, 1841).

Individuals having Mental Illness and individuals having Mental Retardation (now Intellectual and Developmental Disabilities) were isolated and treated appropriately in the Madras Lunatic Asylum, now known as the Institute of Mental Health. For those who couldn't keep up with the rigours of the regular schools, special schools were established in Kurseong (1918), Travancore (1931) and Chennai (1938). In Mumbai (Children Help Society, Mankhurd, 1941), the first residential home for people diagnosed with Intellectual and Developmental Disabilities was founded, and a special school was established in 1944. 11 other centres were then constructed in various locations around India.

The "Right to Free and Compulsory Education for All Children Up to Age 14 Years" was incorporated in Article 41 of the Indian Constitution (1950). Several further schools for children diagnosed with Intellectual and Developmental Disabilities were founded; also an integrated school in Mumbai by Sushila Ben was founded in 1955. Besides this mandate for kids to attend mainstream schools, non-governmental organisations (NGOs) were also opening an increasing number of special schools to try to satisfy the needs of the parents.

There were only 27 schools in the entire nation for people with Intellectual and Developmental Disabilities at that time, as mentioned by to the Indian Education Commission, 1964–1966. Ms. Vakil started training teachers in Mumbai in 1953 to work with students who had Intellectual and Developmental Disabilities. Mrs. M. Clubwala Jadhav introduced special education to instruct people with Intellectual and Developmental Disabilities at the Bala Vihar Training School in Chennai in 1971. Dilkush Special School opened its doors in Mumbai that same year and began special education teachers' training programmes.

The Persons with Disabilities Act (PWD, 1995) was the first attempt by the central government to create legislation for individuals with disabilities. It was later modified and renamed as the Rights of Persons with Disabilities (RPWD, 2016). This Act focused on nondiscrimination and equal opportunities, along with a variety of services that must be developed, including early intervention, preventive measures, training, education and societal benefits.

Later another legislation came into existence, which was named as the National Trust Act 1999 for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities. The act made some special provisions for individuals with Intellectual and Developmental Disabilities. The purpose of this Act was to give those who were unable to speak for themselves and their families more power. It was intended to enable non-governmental organizations (NGOs) and parents' associations to participate in development of support services to a greater extent. Other reviews have been conducted on later acts, policies, and issues, such as advancements in human resources and research (Girimaji and Srinath, 2010). The number of professionals with special education training has increased dramatically, which is one noteworthy development (Narayan, 2007).

1.3. Concept of Intellectual and Developmental Disabilities

Intellectual and Developmental Disabilities (IDD) are conditions that cause notable deficits in cognitive and adaptive skills. "Mental retardation" is no longer used now. Instead, the term IDD is used. Due to social and political pressures, the term used to characterize this condition has changed frequently over time. Finding a term that is the least stigmatizing one, is the primary motivation behind the term searches. Therefore, in the majority of countries today, IDD has taken the place of mental retardation, which was prevalent worldwide until the late 20th century. The term MR was replaced by ID/IDD also in the DSM-V (the Diagnostic and Statistical Manual 5th Revision), and this continues same with the the International Classification of Diseases 11th Revision. (Chavan & Rozatkar, 2014).

Depending on the situation, the term IDD or Intellectual and Developmental Disability may have slightly varied definitions. The term "developmental disabilities" includes both intellectual disability and other childhood-onset disabilities. These disabilities can have a long-lasting impact on a person's thinking (cognitive) or mobility (physical) skill. Difficulties can arise prior to turning 18 and may persist indefinitely. Such physical conditions like cerebral palsy or epilepsy fall under the category of developmental disabilities. Some people may suffer from a condition like Down syndrome or foetal alcohol syndrome, which causes both a physical and an intellectual disability. The "cognitive" portion of this definition, which refers to a condition that is generally related to thought processes, includes intellectual disability. Intellectual Disability is defined by three primary characteristics- having notable deficits in one's intellectual functioning, notable deficits in adaptive behaviour, and start prior to turning 18 years. People with IDD struggle with important life activities like: communication, physical coordination, learning, living independently and Self-help. Children with IDD caused by different biological factors can bring about additional problems, including physical problems, motor difficulties, hearing issues, orthopedic problems, issues regarding vision and health in children. (Hallahan and Kauffman, 2006).

People with IDD have seen profound changes in the past century in all spheres of their lives, including healthcare, work, education, leisure, and housing (WHO, 2000). It has undergone numerous definitions and renamings throughout history. The most of the nations now use the term "Intellectual and Developmental Disabilities" or IDD in place of "Mental Retardation" or MR, which was prevalent throughout the world until the late twentieth century. IDD has now taken its place in DSM-V. (Shree, A., & Shukla, P. C., 2016)

1.3.1. Definitions of Intellectual and Developmental Disabilities

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". 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. Current definitions have shifted from the medical model to the rehabilitative model by characterizing IDD in terms of its functional and educational aspects rather than clinical ones. The following describes how the condition of IDD has changed:

The World Health Organization (WHO) and ICD-10 both define mental retardation (now known as intellectual and developmental disabilities) as a state that results in an arrested or an incomplete development of our mind. It is primarily marked by deficits in skills that are generally developed during the developmental stage and support our cognitive abilities, language and motor development.

It was in the year 2010, that the AAIDD published eleventh edition of the terminology and classification manual of Intellectual Disability (mental retardation) and named it as "Intellectual Disability: Definition, Classification, and Systems of Support" (Schalock et. al., 2010). 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.

The following three criteria determine if a person has an IDD:

1. Below-average cognitive functioning: It speaks of general cognitive abilities like thinking, learning, solving problems, and so forth. An IQ test is one tool used to assess intellectual functioning. An IQ test result of roughly 70 or 75 generally denotes a limit in one's capacity for cognitive functioning.

2. Notable deficiencies exist in at least two areas or more related to adaptive skills: This implies the skills individuals acquire and apply on a daily basis in their life. These skills are:

    i. Social skills - It encompasses the social problem solving skills, the ability to follow rules or obey laws, skills to avoid victimization, interpersonal skills, social duties or responsibilities, self-esteem, gullibility and wariness.

    ii. Conceptual skills - Self-direction, money, time, language and literacy, and number concepts.

    iii. Practical skills - Daily living activities, personal care, career skills, healthcare, routines or schedules, traveling or transportation, safety, use of the telephone, use of money and many other practical activities.

3. Before the age of 18, the condition becomes apparent: One of several developmental disabilities, this disability manifests during the developmental stage, which becomes operationalised prior to the age of eighteen.

Years of work have resulted in a revised definition of AAIDD that better captures the dynamic nature of the field of Intellectual and Developmental Disabilities. In the past, the only criteria used to define IDD were intelligence tests, placing more emphasis on preventative care and upkeep than on therapy and education. The idea of adaptive behaviour has become more and more crucial in recent years in the identification and categorization of individuals with IDD.

The PWD Act of 1995 defined Mental retardation (now Intellectual and Developmental Disabilities), as a condition in which a person's mental development is stopped or incomplete and is particularly marked by subnormal intelligence.

The RPwD Act of 2016 defined Intellectual (and Developmental) Disability as a state in which a person's mental development is stopped or incomplete, particularly when it comes to intelligence.

According to the definition of DSM-5, Intellectual and Developmental Disabilities is considered as neurodevelopmental disorders which start to be seen in childhood and are characterized by the challenges with thinking, feeling and doing everyday life activities. Three requirements must be met in order for an IDD diagnosis to be made using the DSM-5:

Criteria 1. Intellectual functioning deficiencies, as determined by a clinical observation and IQ test, include logical thinking, organising, solving problems, abstract thoughts, judging, academic learning, and experience-based learning.

Criteria 2. Deficits in adaptive skills or functions that substantially hinder the ability of an individual to fulfil his or her social responsibilities and abide by social and developmental norms to live as an independent.

Criteria 3. These deficiencies must have started in childhood.

The concept of IDD is predicated on a minimum of two distinct theoretical frameworks. Those who support the medical model refer to IDD as a "trait," meaning that it is a characteristic that a person has inside him from birth and remains the same over the course of their life. IDD is therefore perceived as an impairment of the body, similar to malformed limbs, or as something which a person lacks and possibly even inherent. (Spitz, 2006). The social model of disability holds that, the cause of an individual's disability is not their impairment, which is a lack of cognitive and adaptive behaviour during a developmental stage, but rather society is the sole reason. It is obvious that the social model shapes the way that people think about this idea today. Luckasson et. al. in 1992 stated,

> “Mental retardation is not something you have, like blue eyes or a bad heart. Nor is it something you are, like being short or thin. It is not a medical disorder ... Nor is it a mental disorder. Mental retardation refers to a particular state of functioning that begins in childhood and in which limitations in intelligence coexist with related limitations in adaptive skill.”

1.3.2. Characteristics of Intellectual and Developmental Disability

Kalgotra and Warwal (2017), talked about the three characteristics of Intellectual and Developmental Disability- medical, behavioural and educational:

1. **Medical Characteristics:** It includes disproportionate head size, bluntness in face, short height below typical, tongue protrusion, and poor coordination when walking.

2. **Behavioural Characteristics:** It includes things like having trouble remembering things, acting slowly, having trouble staying focused on a task for a short period of time, reacting aggressively if demands aren't fulfilled right away, having trouble taking decision, having challenges taking care of own needs, and having trouble following customs of society or grouping rules.

3. **Educational characteristics:** It includes delayed comprehension and slow learning, inattentiveness, difficulty with concentration, anger, forgetfulness, inability to coordinate properly, poorer motor skills, and delayed speech.

Features of individuals with IDD that may impact their capacity to learn academically and adjust to their social, educational, and home environments include:

General Cognitive Abilities: A delayed cognitive development of those IDD people may be the reason behind their slow learning (Wehman, 1997).

Memory Retention and Learning Skill: Adequate learning and memory retention techniques may not come naturally to children with intellectual disabilities, and they may also struggle to recognize the circumstances or behaviours that support these processes. When compared to peers without disabilities, memory retention power and learning skills of individuals with IDD are noticeably below average. Individuals with IDD struggle to apply previously learned knowledge to novel contexts and develop learning skills more slowly than their peers without any disabilities. (Beirne-Smith, Patton and Kim, 2006).

Attention: Children need to stay focused on their learning task for the necessary amount of time and manage any distractions in order to fully comprehend the knowledge. In social and educational contexts, children with intellectual disabilities may struggle to discern and pay attention to pertinent questions (Saunders, 2001).

Adaptive Skills: Individuals with IDD frequently possess adaptive abilities that are incomparable to those without disabilities. Many factors, such as higher degree of distraction, lacking attention, inability to understand social cues, and impulsiveness, can make it difficult for an IDD child to properly learn and apply their skills (Hardman et al., 2008).

Self Control: Self-regulation, or the capacity to moderate or control one's own behaviour, is a concept that is linked to task rehearsals. (Shonkoff and Phillips, 2000). IDD people are thought to have underdeveloped cognitive functions, which accounts for the differences in their learning pace. Retention, rehearsal techniques, skills in organization, and control over the learning procedure are all significantly impacted by the absence or inadequate development of these abilities. (Erez and Peled, 2001; Hunt and Marshall, 2002).

Development of Language and Speech: Individuals with IDD may experience difficulties understanding language, speaking it aloud, and formulating sentences. Rather than being related to weird language use, difficulties related to language are frequently linked to delays in development of language skills. (Moore-Brown and Montgomery, 2006; Beirne-Smith et al., 2006). There is a positive correlation between the severity of language and speech issues, and the severity and causes of IDD. Language difficulties are less common in people with lower level of IDD. (Moore-Brown and Montgomery, 2006).

Motivation: It is common to characterize individuals with IDD as having low motivation or acting in an outwardly directed manner. They may appear like they don't have any clear goal and are not motivated because of past failures and the anxiety they have felt. (Shree, A., & Shukla, P. C., 2016)

Academic Excellence: Children having mild to moderate levels of IDD often struggle with achieving academic success due to inefficient cognition. (Hughes et al., 2002). Children with IDD may learn basic mathematical computations, but they may not apply those concepts correctly when solving problems. (Beirne-Smith et al., 2006).

1.3.3. Classifications of Intellectual and Developmental Disability

The DSM-5, published by American Psychiatric Association, and the AAIDD are two organizations that classify Intellectual and Developmental disability. The seriousness of IDD is determined by how much support a person needs. Over the past few years, a variety of classification schemes for IDD children are made. Four categories are used now to differentiate the severity of IDD in the 1973 and 1983 AAIDD definitions. Those are mild, moderate, severe, and profound IDD. (Sattler, 2002)

Level of IDD	IQ
Mild	55-69
Moderate	36-51
Severe	20-35
Profound	< 20

This classification can also be done based on the educability expectations:

Mild Level of Intellectual Disability (Educable): It is similar to what was formerly known as the "educable" educational category. About 85% of people with the disorder belong to this group, which makes up the majority. Individuals with this level of ID usually exhibit minimal loss in the sensory motor domains, develop interpersonal and social skills during their preschool years (0-5 years age), and are frequently dissimilar to children without IDD afterwards in life. They can learn up to about the sixth grade in terms of academic skills by the time they are late teens. They typically develop social and professional skills in adulthood that are sufficient for minimal self-sufficiency. Nonetheless, they may require direction, support, and monitoring, particularly in atypical social or financial stress scenarios. People with mild IDD can typically live happily in society with the right support.

Moderate level of Intellectual Disability (Trainable): It is comparable to what was formerly known as the "Trainable" educational category. It will be untrue to say that people with moderate IDs cannot gain anything from educational programmers. This subset accounts for approximately 10% of all individuals with IDD. Most people with this level of IDD learn how to communicate in their early years of life. They gain from receiving vocational training and are capable of taking care of themselves with little to no supervision. They can even gain from training in social and professional skills, but they are unlikely to advance academically past the second grade level. In well-known locations, they may acquire the skills to travel alone. Relationships with peers may be hampered by their inability to recognize customs during teenage years. Most adults are capable of doing works which are either untrained or semiskilled under monitoring. They settle in well to community life as well.

Severe Intellectual Disability (Custodial): Approximately 3% to 4% of people with IDD belong to the severe IDD group. They acquire little to no interpersonal communication skills in their early years. Aside from the school-age phase, they can receive training in basic self-care techniques and possibly even learn to speak. Only pre-academic lessons, such as learning the alphabet and basic counting, is beneficial to them. They can, however, pick up a skill like being able to read some "survival" words by sight. When they're adults, they may potentially be able to take on easy task under close supervision. The majority of them settle in well to lives in society, in houses alongside their families; however, some of them have a disability that necessitates special nursing care or other considerations.

Profound Intellectual Disabilities (Custodial): About 1% to 2% of people with IDD are in this category. The majority of people with this label have an acknowledged neurological disorder that is responsible for this condition. In the early years of life, they exhibit significant impairment in their ability to use their senses and their muscles. A setting where parents are constantly involved and providing guidance can foster the best possible development. If appropriate training is given, development of motor skills, taking care of oneself and communication abilities may all increase.

AAIDD employs a categorization scheme that takes into account the kind and level of assistance an individual with IDD needs in order to function in their natural environments, which are their home and community. The AAIDD suggests four tiers of assistance:

i) Intermittent: In this case, assistance or support is given as required. These assistance may be periodic. Assistance is not always required by the person; it is only temporary and happens while on life transitions.

ii) Limited: The need for supports or assistance is constant; the amount of time needed may be restricted, but it is not periodic. The expenses may be less than the ones connected with more significant levels of support, and fewer employees may be needed.

iii) Extensive: Assistance here are defined by regular participation in at least certain environments like the workplace or home. Time limits do not apply to this support. Home-living support and a stable job are essential.

iv) Pervasive: Supports need to be strong and consistent. They may be necessary for life in the environment and must be supplied in a variety of settings. Comprehensive or time-limited assistance are usually more minimal than pervasive ones, involving fewer staff members.

1.3.4. Causes of Intellectual and Developmental Disability

Between one-third and half of cases of IDD in children have an unknown cause. Parents are the cause for around five percent of cases (Daily et al., 2000). Any illness that hinders brain development prior to, at the time of birth, or during childhood can result in IDD. While hundreds of causes are detected, the cause is still unidentified for roughly one-third of those suffering. The conditions Down syndrome, fragile X syndrome, and fetal alcohol spectrum disorder (FASD) are the three main acknowledged causes of IDD. According to McLaren and Bryson (1987), an organic or biological basis accounts for the disorder in about 70% of people having severe IDD and 50% of people having mild IDD. The most prevalent reasons are:

The genetic conditions: Gene combinations gone wrong, aberrant genes passed on from parents, and other factors can sometimes result in IDD. The most common genetic disorders are neurofibromatosis, congenital hypothyroidism, Williams syndrome, Down syndrome, Klinefelter syndrome, Fragile X syndrome (which is common in boys), and Prader-Willi syndrome.

Issues during pregnancy: Abnormal development of the fetus can result in IDD. For instance, a problem with the cell division of the fetus during its growth can exist. A child with an IDD may also be born to a pregnant woman who consumes alcohol (FASD)) or contracts an illness like rubella while on her pregnancy.

Issues at birth and birth defects: Of all the conditions, low birth weight and premature birth are the most accurate warning signs of major birth defects. A newborn that experiences difficulties during labor and delivery, such as low oxygen levels, may suffer brain damage that results in IDD.

Issues after birth and exposure to specific diseases or toxins: Insufficient or delayed healthcare treatment can result in intellectual disability from illnesses such as whooping cough, measles, or meningitis. The ability to think clearly may also be affected by exposure to toxins like lead or mercury.

D**eficiency of Iodine:** In developing nations where iodine deficiency is endemic, the primary avoidable cause of IDD affects about 2 billion people globally. A thyroid gland enlargement known as goiter is also brought on by an iodine deficiency. Mild cognitive impairment is more common than full-blown cretinism - the term used to describe IDD resulting from severe iodine deficiency. Iodine deficiency is a serious problem for inhabitants of some parts of the world due to natural dearths and poor governmental performance. There are 500 million people in India who are deficient, 54 million who have goiter, and 2 million who have cretinism. (McNeil, 2006).

Malnutrition: A decreased intelligence is frequently caused by malnutrition in famine-affected parts of the world, such as Ethiopia and countries dealing with long-term conflicts or war that disrupt cultivation and transportation (Michael, 2006).

1.3.5. Related and Associated Disorders

Individuals with IDD often have co-occurring conditions like, neurodevelopmental, medical and physical, and mental health conditions. Numerous brain abnormalities that result in or contribute to IDD are also associated with other illnesses or mental health problems. The following medical and mental health conditions (in addition it may also be seen in individuals without IDD) can also coexist with intellectual disabilities:

- Attention-deficit hyperactivity disorder (ADHD).
- Autism spectrum disorder (ASD)
- Impulse control disorders.
- Mood disorders, especially anxiety disorders and depression.
- Movement disorders like Spacticity, Parkinson's Desease, Tourette Syndrome
- Cerebral Palsy (CP)

1.3.6. Treatment

A person with an IDD will always have it in his life. Early and continuous intervention, according to the American Psychiatric Association, may enhance functioning and allow the IDD person to survive for the rest of his life. Individuals with IDD often lead complicated lives due to concurrent illnesses and the underpinning medical and genetic conditions behind it. After IDD is diagnosed, the focus of care is on the person's needs and strengths as well as the supports required for him or her to function in the community, at home, at school or workplace.

Services are available to help families and individuals with IDD to integrate fully into their wider communities. Numerous kinds of services and support networks are available to assist, like:

- Early intervention (infants and toddlers).
- Special education.
- Family support (for example, respite care support groups for families).
- Transition services from childhood to adulthood.
- Vocational courses.
- Day care centres for adults.
- Accommodations and living choices.
- Case handling.

Furthermore, there are other people who can provide support: friends, family, coworkers, neighbours, schools, medical teams, or the service systems. Support services may include professional coaching services as a form of assistance. Individuals with IDD can definitely play important, productive roles in society if they receive the right support.

1.4. Parents of Intellectually and Developmentally Disabled Children

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.

In programmes involving their differently abled children, parents and other family members are actively participating on each and every level. Each child, regardless of whether they are considered "normal" or "disabled," makes his or her first friends, experiences his or her first things, and grows up in the context of their family. Like everyone else, individuals with IDD require care, compassion, and attention. They seek a safe space within their families and need the acceptance of others. The family is the oldest institution in human history and the foundation of social structure. "Family" in its broadest sense, refers to a group of individuals identified as a distinct social class or are connected to one another through marriage or blood ties.

A person is socialised in the family, which is an everlasting relationship of parents and children. The members' happiness and the child's socialisation are its two main goals. Sincerity, sympathy, self-admission, and a sense of responsibility are all crucial traits that children learn in their families. The character cultivated in the home is what aids the child in developing into a significant and dutiful member of society. The child will progressively learn about the society in which he or she lives as they grow up, surrounded by brothers, sisters, parents, and occasionally, grandparents and other relatives. Socialization is a process that continues throughout life and is not just limited to interactions between parents and their children or to childhood.

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.

1.4.1. Types of Crisis faced by Parents of IDD Children

Menolascina (1967) and Wolfensberger (1967) termed three types of emotional distress in parents who have children with disabilities.

I. **The Novelty Crisis:** This type of crisis is not a response to the disabled child. Such a crisis is the result of a change in the whole life and circumstances of the parents when a disabled child is born in the family. All the dreams and hopes of those parents are shattered and the parents have to accept this terrible truth and rebuild a new chapter of their lives. In this situation, many parents blame the doctor, some blame God.

II. **The Value Crisis:** Such a critical situation occurs when parents love their child but cannot accept the child's disability. So otherwise they ignore their disabled children. In such a critical situation, the life goals, hopes and aspirations of a happy couple sink deep into despair. Such a crisis is evident in ordinary middle-class families who are too optimistic about their children's future. Theories have been proposed by many researchers about what the stages of parental grief and pain are seen during this time. The following stages of parental grief and pain may not be the same for everyone:
    - Guilt and shame
    - Denial and loneliness
    - Anger
    - making a deal with God
    - Sadness and despair
    - Excessive involvement
    - Authoritarianism
    - Acceptance or rejection

III. **The Reality crisis:** There are many real problems that parents have to face in such a critical situation. Parents at this stage face difficulties in arranging the extra labor, time, perseverance and money required for raising, treating, educating, vocational training, caring for a disabled child. For a child with a disability, parents have trouble going out together or participating in social activities together. Parents also worry about who will take care of their severely disabled child after the parent's death. The problem of reality crisis is so deep that in some cases the mother of a disabled child suffers great mental pain and depression, becomes physically ill, quarrels and finally isolates herself from society and family and suffers loneliness. But usually in those families where there are no other family conflicts or emotional problems and where the married life is happy, reality crisis cannot take extreme form.

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CHAPTER - II

REVIEW OF RELATED LITERATURE

2.1. Meaning and Purpose of Review of Related Literature

The literature review, as defined by Creswell (2014), is a written overview of books, journal articles, and other documents that summarizes the current and old status of information regarding the subject of the research study. An overview of all the writing that has been done on a specific subject, theory, or research question, is known as the literature review. An information source is what the word "literature" refers to. The researcher will learn about previously completed researches on a selected topic from the literature. This is significant because the researcher prefers to avoid duplicating work unless there is compelling reason to do so (such as a recent development in the field, the need to test a theory on a different population, or even just confirming whether the research can be replicated). Reviews of related literature typically act as a backdrop for longer works (such as those found in theses or research proposals) or they can stand alone. An effective literature review is much more than just a list of references; it not only analyzes but also summarizes data regarding important themes or problems.

L.R. Gay (2016) defined, “The review of related literature involves the systematic identification, location, and analysis of documents containing information related to the research problem.” Gay claims that identifying prior research related to the researcher's topic of choice is the main goal of a literature review. This information not only keeps researchers from inadvertently repeating the work of others, but it also provides them with the knowledge and perspective necessary for putting their own research within a rational context. The literature review entails a thorough examination of books, articles, and other materials that are relevant to the problem as defined. The study is significant because it informs the researcher as to whether other researchers have already addressed the issue that the present researcher has discovered. It also provides the researcher with information about the current state of the problem, methods that other researchers have employed to study it, and other pertinent facts.

A literature review is more than just a search for information; it also identifies and describes the connections between the body of existing literature and researcher's area of study. Literature review helps a researcher learn what has already been written about a subject and how the different contributions relate to one another. It will make possible for the researcher to ascertain how much each source, like articles, journals, books and so on, contributes to the subject. Through literature reviews, a researcher can also determine research gaps and even unanswered questions, as well as identify and resolve the matter.

The present chapter deals with the various studies related to parents and their children having Intellectual and Developmental Disabilities (IDD) conducted in abroad as well as in India.

2.2. Studies Conducted in Abroad

Kruithof, Willems, Etten-Jamaludin, and Olsman (2020) conducted their research on “Parents' knowledge of their child with profound intellectual and multiple disabilities: An interpretative synthesis”. Parents need to be conscious about the profound intellectual and multiple disabilities (PIMD) found in their kids in so they can help and provide adequate support to them. The aim of the study was to look at what parents know and how they use it. The researchers picked fourteen studies after doing a narrative interpretative analysis and searching CINAHL, Philosopher's Index, PubMed and PsycINFO. The research findings showed that parents had a special and firsthand understanding about their child with PIMD, acquired through frequent interactions with them. The findings of the research also suggested that they used their knowledge in essentially two ways: firstly as experts, they had firsthand knowledge about how their children communicate, feel, and experience pain; and secondly as advocates, they used those information to question how accurate medical techniques are or to make it more widely accepted in the fields of medicine as well as in health care.

Mash and Johnson (1983) investigated 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. The study included 41 families with children who were hyperactive and 51 families with children who were normal. The instruments for the data collection included the parenting stress index, the hyperactivity rating scale, the child behaviour checklist, and the parenting sense of competence scale. The findings showed that parents who had hyperactive children showed lower parenting self-esteem than parents who had typical children. Mothers who had hyperactive children, particularly those with younger ones, reported feeling significantly more stressed out. Self-esteem of parents and views regarding the child problem were found to be inversely correlated, while ratings of their disturbance and mothers’ stress were found to be positively correlated.

Cavkaytar, Ceyhan, Adıgüzel, and Uysal (2012) in their study, entitled “Investigating Education and Support Needs of Families Who Have Children with Intellectual Disabilities” tried to define the family needs due to having IDD children. In the study, a descriptive survey model was employed by the researchers. Data was gathered through semi-structured interviews. Nine special education schools under the Ministry of Education's supervision—known as Training Application Schools (Eitim Uygulama Okulu)—were used for the study. In addition, 18 administrators, teachers, and 38 volunteer parents of IDD children participated in the study. Themes that came out from the interviews included social support systems, personal growth, child-rearing abilities, the adjustment process, knowledge of special education programs and school policies, and children's health. Administrators, teachers, and parents all had needs areas that were similar to one another, despite minor variances in the percentage of each group's needs. The findings of this study may be used to build future programmes and design new ones based upon the requirements of families having IDD children.

Tigere and Makhubele (2019) did a research related to the experiences of parents of differently abled children living in Sekhukhune district of Limpopo province. Parents belonging to those rural area of South Africa, experienced problems while raising their differently abled children for the scarcity of resources and adequate services. The study focused on the experiences and problems of parents who had children with various types of disabilities. Researchers took 14 participants as sample, whose children were suffering from disabilities. For data collection, an interview schedule was used by the researchers. The collected data were thematically analysed, and emerging themes were grouped together. The data showed that the majority of the participants had different perspective and knowledge about the cause of the disability found their child. The respondents further believed that the traditional African medicines, spirituality, or medication could provide a "cure" for disability. The findings revealed that the majority of fathers did not wish to be associated with disabled children. The study also revealed a theme of stigmatisation of parents. It was believed that parents were atoning for the wrongdoings they committed or engaging in witchcraft, resulting in name labelling.

Lowers-Roach (2021) conducted a study to explore the challenges and experiences parents or guardians of school-age children with IDD faced in Jamaica. Because of the relative poverty and lack of resources in Jamaica, raising a child with special needs might be challenging. Using a qualitative grounded theory, the researcher was able to analyse the issues parents of children with IDD faced in great detail. 21 parents and guardians of school-age children with IDD comprised a diversified purposive sample. The age range of the children included in the study was three to eighteen. The interviews were transcribed, recorded, and analysed into concepts and constructs in order to create a grounded theory. The primary obstacle and underlying social problem they encountered, as indicated by the findings, was a deficiency of resources and assistance. The lack of resources left parents and guardians feeling as though their children had no hope or normalcy, which disappointed them. They found a dearth of understanding, empathy, and professional support in the medical field. Five complementary theoretical constructs encircled the central idea of the difficulties they faced as a burden. These were social stigma, professional awareness, emotional and mental well-being, and challenging condition.

Gill and Liamputtong (2011) conducted a qualitative study exploring the experience of stigma and problems of mothers having children with Asperger's Syndrome (AS). Fifteen women took part in in-depth interviews, and six of them produced a requested diary that provided a more thorough understanding of the problems these mothers faced. Findings revealed that the mothers felt stigmatised by how other people saw them as well as their children due to the appearance and unusual behaviours of their children.

Malekshahi, Rezaian, and Almasian (2020) conducted a study on Intellectually Disabled Children and Their Parents ’Problems. The current investigation sought to ascertain the psychological issues faced by the parents of children with intellectual disabilities (IDCs) who are receiving assistance from the Iranian State Welfare Organization located in Khorramabad. The participants were the parents of IDC who were receiving services in Khorramabad in 2015 from the State Welfare Organization of Iran. A questionnaire about demographics and social and psychological issues was used to collect the data. In this study, 144 IDC parents took part and filled out a questionnaire through in-home interviews. The findings revealed that IDC families dealt with a variety of emotional, financial, and educational challenges in addition to numerous social and psychological issues related to raising their child.

Mann (2013) examined the experiences and problems of mothers caring for children with autism living in Jamaica using a qualitative and exploratory methodological approach. The study also looked at the needs that were perceived to be unmet. Mann discovered that children diagnosed with autism spectrum disorders were among the most commonly seen special needs children in Jamaica, as well as one of the least well-served demographics. Contributing factors included 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.

Tekola, Kinfe, Girma, Hanlon, and Hoekstra (2023) used detailed interviews to investigate the experiences of parents (four fathers and fourteen mothers) who were raising developmentally disabled children in both cities and rural areas of Ethiopia. The researchers contended that an understanding of developmental disabilities through the lens of the locals, as well as the difficulties and needs of children as well as families, may be gained from the personal experiences of those parents. Parents' early detection of developmental delays or differences in their child were influenced by their cultural and religious beliefs, which also influenced the support they sought. Parents encountered discrimination and a lack of empathy from others. Depending on the parents' residential situation, the experiences of them with certain difficulties, like a lack of suitable services, differed. Particularly single mothers had to deal with a variety of interconnected issues, such as poverty, stigma, and no social support.

Niedbalski (2021) analysed the phenomenon of parents 'managing the stigma of their child's disability. Whether to disclose or keep the child's impairment a secret can help manage stigma. The researcher used Erving Goffman's concept of stigma to highlight how helpful it is to comprehend how parents of IDD children manage prejudices or stigma. Data analysis was carried out following grounded theory. According to research findings, 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.

Erikson and Upshur (1989) conducted an exploratory study to see the differences between mothers of children with disabilities and without disabilities in their perceptions regarding the burden of child care. Father's participation in childcare is often associated with social support. The sample consists of 202 mothers of infants with Down's syndrome, motor impairment; developmental delay was recorded as self-reports based on the mothers perception. The results indicated significant differences on childcare taking, difficulty in feeding, bathing & dressing and care taking time. The second finding was that 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.

Siamaga (2011) conducted a study on parenting stress for having child with Mental Retardation (now IDD). This systematic review aimed to document the current bibliographies of research on the stress experienced by parents of children with IDD, to compile the secondary parameters and various factors based on current research reports on the impact of IDD children on parents; not only that but also to illustrate the intercultural nature of the stress experienced by those parents. The investigator conducted a thorough review of scholarly articles disseminated through various international academic databases, for example, Medline, Elsevier, Sage and so on. The reviews by Siamaga proved that the 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. Additionally, there were some individual factors that increased the level of parenting stress, such as the relationship between husband and wife, the parents' attitude toward s their children's disability, the coping mechanisms the parents employed to deal with the child's daily challenges, and the behavioural issues of their children. The review concluded by showing that, even in countries with disparate cultural backgrounds, the severity of symptoms and the effect of a child's disability on the parents were similar.

Dauglas, Redley, and Ottmann (2016) conducted their research In order to characterize the support requirements of parents raising an IDD child during the first calendar year of life. For their investigation, they employed a qualitative as well as a descriptive methodology. In Victoria city of Australia, parents of eleven children with IDD participated in a semi-structured interview. Digital recordings of the interviews were made, transcribed, and subjected to thematic analysis. Result of the study discovered three major areas of support needs to assist parents of IDD children to provide effective care for their children in the first year of life. The first was emotional support, the second was support for information; and the third one was assistance in establishing a connection with peer networks. The results also showed that parents were not always receiving the support they needed. The study came to the conclusion that it is critical to reevaluate the ways in which the midwives and the nurses will offer pertinent assistance that is sensitive to the needs of parents.

Mendoza, Vera, and Hurtado (2015) conducted their research to study the level of family satisfaction of parents in Mexico who had IDD child. With the help of discriminant and cluster analysis, their study sought to determine the traits and distinctions between fathers and mothers regarding the family satisfaction level as well as mediating factors. The results identified three groups of families: first one was “very satisfied”, second was “satisfied”, and last one was “dissatisfied”. Parental support was found to be the most significant factor in the analysis related to sex. The wide variety of families and the variations in roles in raising IDD children made it possible to consider parental support as being one of the the most crucial factors in enabling sufficient levels of satisfaction in their family. The study came to the conclusion that those factors also need to be included in some intervention programs.

Abani, Anislag, Budiongan, Cagape, and Paz (2023) in their research, investigated parents' real-life experiences with accepting their child’s condition of IDD. In the study, a qualitative methodology was applied. A purposeful sample was taken. Six parents of IDD children participated in interviews that were semi-structured. The main themes and meanings that emerged from the parents were identified and interpreted using a thematic evaluation. The results demonstrated how complex and multifaceted the process of accepting an IDD child was. 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.

Beveridge (1982) conducted a study which showed some common needs that were represented by the following: planning for child’s future, diagnosis and prognosis information, 25 out of 31 aids for assistance, resources in the community, and technology training to support the development of an IDD child. Parents of IDD children also expressed the need for respite care, self-help group initiation, daycare services training, and identification of community resources.

Baker, Laden, and Kashina (1991) investigated how parent education affected IDD children. 49 families, comprising 27 out of 31 individuals with IDD underwent assessments both prior to and following the determination of marital and parental measures. Parents expressed great satisfaction with the programme, and 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. The parents who said they had the less impactful teaching, started training, and they also reported feeling less satisfied with their marriage and more stress about their kids. The findings indicated that parent education programs might be more successful in the long run if they also improved marriage satisfaction, made parents more adaptive, or reduced stress areas that were associated with worse and lengthy outcomes.

Baker and Blacher (2007) investigated how parents perceived the positive aspects of having a n IDD child. They conducted two studies for this purpose. First study involved 282 mothers who had adolescents with moderate to profound IDD and second study involved 214 parents who had younger kids with or without IDD. Findings suggested that behaviour problems had inverse relationship with positive impact. Additionally, positive impact acted as a moderator variable between parenting stress and behaviour problem.

Gavidia and Stoneman (2006) investigated how everyday hassles and stresses affected parents of IDD children with regard to problem-oriented coping mechanism and their marriage related adjustments. Findings suggested, both mothers and fathers viewed their marriages negatively when everyday hassles and stress level were more extensive as well as higher. 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. Fathers who reported fewer everyday stresses and hassles and more problem-oriented coping mechanisms, were found to have positively adjusted to their marriages, as were mothers.

Greer, Grey, and McClean (2006) conducted a study on 36 mothers of children with IDD who were between the ages of 5 and 8, on their coping & positive perceptions. Five questionnaires based on self-report assessing behavioural and emotional issues, family support, care and demand levels, positive perception, and coping mechanics were completed by the participants. 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. They also reported that their child act as an embodiment of family closeness, strength, and opportunities for personal development.

Oti-Boadi (2017) investigated the experiences of Ghanaian mothers of IDD children. Finding the difficulties and coping mechanisms related to parenting an IDD child was the primary goal of the research. In the study, the researcher employed a phenomenological approach. Using purposive sampling, 11 mothers of IDD kids going to a special school were chosen. Mothers of those IDD children were interviewed about their experiences. Six key themes were emerged from the data analysis: 1. emotional responses; 2. difficult caregiving situations; 3. social responses; 4. awareness about the condition; 5. Suspected cause, and 6. coping mechanisms. The result showed that a mother raising an IDD child had to deal with a number of stressful situations. Additionally, it was seen that mothers discussed the significance of their coping mechanisms, such as hope, support, and spiritual convictions, in helping to raise their IDD children. The study emphasized how difficult it is to raise an IDD child and how helpful coping mechanisms are in assisting mothers in navigating the caregiving journey with their kids.

Hastings, McDermott, and Still (2002) conducted a study entitled “Factors Related to Positive Perceptions in Mothers of Children with Intellectual Disabilities”. The primary objective of this research was to investigate what factors were associated with mothers' favourable opinions of their IDD child. In order to evaluate the coping mechanisms, social support, and aspects of positive perception of mothers of IDD children, samples comprised 41 mothers. This was accomplished using a self-report questionnaire. The findings showed that reframing techniques for coping was positively correlated with mothers' opinions regarding their IDD child as an expression of satisfaction or joy as well as a source of energy and closeness to their families. Reframing mechanisms of coping, the value and generosity of support from relatives and close friends, and the caregiving requirements were all positively correlated with mothers' views regarding their IDD child as an indicator of development in oneself and maturation.

Ramzan et. al. (2022) sought to determine the level of parents’ stress experienced by Pakistani families raising developmentally disabled children. The purpose of their study was to determine the factors that Pakistani parents of IDD or ASD had in common as an effect of parenting. 100 parents of ASD children and 91 parents of IDD children, consented to participate in the study. According to these results, 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. The highest percentages were shown by parents of IDD children (61.1%) and parents of ASD children (72.2%). The stress level of parents of both children was higher. The study suggested that parents who experience greater stress should seek prompt counselling regarding the challenges they face when raising a differently abled child. They will be knowledgeable about how to take their minds off of the most stressful situations.

Lefakane and Maseko (2023) carried out a study to investigate how parents perceive their role in helping students with IDD move from regular schools to special education schools. Eight learners from a single general elementary school in South Africa, were purposefully selected and took part in interviews with semi-structured questions. It was basically a qualitative case study. The results showed that identifying the IDD students was very difficult having overwhelming, mixed feelings, due to parents' education and cultural background. By providing counselling as well as therapeutic treatment during the transition period for overcoming psychological issues, the availability of psychosocial and emotional services in regular schools and the availability of training for teachers in skills addressing the need of parents' support, all would benefit parents and their IDD children.

A family's confusion, sadness, and disappointments increase when an IDD child with is born, particularly among the mothers. **Raliphaswa, Maluleke, and Netshikweta (2022)** conducted a study so that they could investigate and characterize the difficulties faced by mothers of IDD children. The study was carried out in few hospitals in Vhembe district. Based on the distinctive requirements of their IDD children and their early knowledge of the condition and its treatment, mothers of IDD children reported anxiety, panic, shame, and economic stress.

Beighton and Wills (2017) conducted a study to know whether parents could recognize the positive effects of raising an IDD child. Though it's not clear till now what exactly defines a "positive," the study shared what actually parents believed to be positive with regard to parenting IDD child. A total of seven key concepts emerged: 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 have on the larger community. An interpretive analysis of those concepts showed that the majority of the beneficial aspects were meaning-focused mechanisms for coping. They enabled parents to effectively adjust to the demanding experiences of raising their IDD children, and as a result, they could be candidates for meaning-focused therapies as well.

Jones, Prout, and Kleinert (2005) carried out a study on the aspects of quality living for developmentally disabled adults. They looked into whether those developmentally disabled adults and the normal people had different quality of living. Scales assessing the levels of decision-making and mental well-being, along with other particular variables, showed differences. The quality lifestyles of those two groups were also different; the developmentally disabled group had a lower quality lifestyles overall. When compared to the normal people, developmentally disabled people have a significantly lower quality living, according to the overall results.

Salinas and Tiamzon (2022) conducted a study in order to better understand the living experiences of parents of IDD students. In order to explain their daily life experiences, difficulties, and coping strategies as parents of IDD students, the researchers completed an online interview of six parents. Themes from this current study included the road towards accepting the child, the act of generosity, and the secret to effective co-parenting. The topics were examined in a way that inspired and meaningfully conveyed the parents' experiences of parenting an IDD child. The results of this study encouraged parents of IDD students, special as well as general educators, NGO workers and others to advocate for increased awareness of parenting experiences, challenges and strategies for coping up with the situation in the wonderful journey of raising an IDD child.

Baxter, Cummins, and Yiolitis (2000) conducted a study to in order to find out how parenting stress was related to family members who had children with disabilities as well as without disabilities. The study was conducted over an extended period of time. For seven long years, the researchers looked into the stresses in daily life that parents attributed to their family member with IDD with regard to parental worry. They also looked into the stress that parents attributed to the youngest sibling, who was not differently abled. Consequently, it was discovered that the 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. In fact, the majority of the differences in describing the stress linked to that disabled family member could be explained by the stress linked to the non disabled sibling.

Abasi, Fadakar, Khaleghdoost, Sedighi, and Atrkar Roshan (2010) conducted a survey in order to ascertain the issues faced by families of IDD children in Guilan Welfare Centres. 140 parents of IDD children who were receiving protection from a centre dealing with IDD were the subjects of this descriptive and cross-sectional investigation. The tool utilized in the study, comprised a questionnaire that was self made and that was designed to evaluate the issues faced by families of IDD children The samples were interviewed after being selected through a survey. SPSS 14, fisher test and chi-square were used to analyze the final data. Results revealed that 65.7% parents had experienced financial difficulties.

Ytterhus, Wendelborg, and Lundeby (2008) reported that parents of 3-6 year old IDD children experienced parenthood similar to parents of normal children, though they had difficulty during the diagnosis and finding the treatment options. A major turning point generally occurs when the child reaches eight years of age with the influx of practical and emotional challenges/transitions. The practical challenges were in terms of increased workload because the child had grown older and physically bigger in size, greater supervision needed in order to avoid the consequences of child's spontaneous activities and difficulty in getting services, support workers and help from family members and neighbours.

Lam, Yau, Franklin, and Leggat (2022) conducted their research in order to better 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. The study was qualitative in nature. The researchers completed semi-structured interviews of seven parents. In order to better understand the experiences and mentality of parents of IDD son or daughter towards their sexual urges, Interpretative Phenomenological Analysis was used in the study. Results indicated that 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. Parents also showed mixed emotions, displaying grief and love, when talking about their son's or daughter's sexuality.

Aldosari and Pufpaff (2014) studied on "Sources of Stress among Parents of Children with Intellectual Disabilities: A Preliminary Investigation in Saudi Arabia". The objective was to identify the differences in daily life stressors experienced by Saudi Arabian parents of male IDD children. Parents whose male child was diagnosed with an IDD and went to a special school or a regular school in Riyadh, Saudi Arabia, were included as the sample. The results of the research showed that 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.

Perkins and Haley (2010) conducted a research and investigated experiences of caregivers about compound caregiving and how their quality living was related to it. The study looked at ninety-one elderly parents who were living together with a young adult IDD daughter or son. The result revealed that 37% of them were found to be the compound caregivers, mostly to their parents, in-laws, and husband or wife with severe health diseases. The study also showed that, in contrast to non-compound caregivers, those compound carers were more inclined to want to keep their adult disabled daughter or son with a homely atmosphere. The study concluded that the major difficulties experienced by those caregivers while doing caregiving was a having no time for personal developments, no support help from neighbours or friends, physical fatigue as well as stress.

Chadwick et. al. (2013) conducted their study to map the life experiences family carers of IDD people in Ireland. They used qualitative method. Ten focus groups comprising 70 siblings as well as parents of IDD children were involved in the research. Data were thematically analysed. Result showed that caregiving for someone in the family with IDD was found to have been a constantly changing and adaptable process. The study discovered the key theme as family members' well-being and the challenges they faced in their entire life. 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.

Islam, Farjana, and Shahnaz (2013) conducted a study on stress which was felt among parents of IDD children. The objective was to assess the levels of physical as well as mental stress experienced by parents of children with IDD versus parents of children without such disabilities. It was a cross-sectional investigation. Results showed that parents of IDD children with had a substantially higher anxiety score than parents of children without IDD. Compared to parents of children without IDD, parents of IDD children had a considerably greater mental anxiety score. Physical anxiety score was insignificantly greater in parents of IDD children than the parents of children without IDD. 67.5% fathers and 71.4% mothers of IDD children reported more mental anxiety compared to physical one.

Fairthorne, Jacoby, Bourke, Klerk, and Leonard (2015) conducted a research entitled "Onset of maternal psychiatric disorders after the birth of a child with intellectual disability: a retrospective cohort study". After the birth of the first IDD child between 1983 and 2005, the study estimated the prevalence of new psychological conditions in mothers as well. These incidences were next compared to those mothers having no IDD or ASD children and born during same time zone. 277,559 mothers were selected as samples who had no history of psychiatric problems. Then the study did a comparison of the prevalence of psychological disorders between mothers with an IDD child and mothers without a n IDD or ASD child. Negative binomial regression was employed for analysis. Results revealed, 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. The findings also revealed that mothers having Down Syndrome children and still not having any mental health disorders in life, showed more strength and energy and had not a single issue in their psychological health.

Gardner and Harmon (2002) described, in their study, the experiences of six strong mothers of IDD children. The study was phenomenological in nature and used qualitative method. The study involved conducting detailed interview of those mothers. The study discovered that mothers IDD children used networks of similar parents for sharing information regarding services. Those mothers also mentioned the importance 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.

Yang and Jing (2006) conducted a study to analyze the psychologic health status, especially the influential factors and intervention conditions of parents of IDD children. Data had been collected from English articles published from January 1998 to October 2005 in PubMed about psychologic condition of parents of IDD children. Findings suggested, parents' emotional condition for having

IDD children are effected by many different factors and complex process, different model lead to various results, which indicated that different test methods should be used to describe these reactions.

Shrestha, Adhikari, and Pokhrel (2022) had conducted a study on parental stress and coping mechanisms. The primary goal of the research was to determine the stress and coping mechanisms experienced by parents of IDD children in Kathmandu. It was a cross-sectional study that was descriptive in nature. 222 fathers or mothers of IDD children made up the samples. Probability sampling was done. The researchers collected data through interview and used the Nepali-translated Parental Stress Scale. The results showed a significant correlation between the amount of stress and the parent's educational attainment, the existence of co-disability in the IDD child, and the child's relationship to them. 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. Hindu and literate parents demonstrated a high level of coping.

Rosaleen (1994) studied on families with an IDD child. The researchers, in their study, reviewed the both immediate and long-term requirements and the service provided to those families. The Findings suggested that the services provided should not be restricted to teaching functional skills those individuals with IDD. It concluded that certain techniques for sustained care in society might be ensured by a holistic strategy that included assistance for the parents as well as the non disabled siblings.

Arzeen and Irshad (2021) studied the mental anxiety, support from society, and fulfillment in life of parents of IDD children in Pakistan. 75 fathers as well as 75 mothers of IDD children were purposefully chosen from Peshawar. Findings showed, in Pakistan, mothers suffered from greater mental stress, anxiety, and depression, whereas fathers stated higher levels of support from society and satisfaction with life. The parental role in the life of their IDD kid was a significant area as it may lead to numerous issues in society when mental health of those parents got ignored.

Budek, Küçük, and Civelek (2018) conducted an investigation into the experiences of mothers raising IDD children. A qualitative approach was taken in the study. It made use of a procedure that would share genuine observations along with helping those mothers in communicating their feelings regarding their own unique experiences. The researchers studied how mothers of IDD children took care of their children by using a qualitative method that looked at their life experiences in a deep way. The findings revealed that "care management," “uncertainty”, “impact", “stigma", "search for meaning” and "relationship" were identified as interest categories. The study concluded that not all mothers IDD children viewed their experiences with a negative mindset. Some of them might not have any problem taking care of their child. Nearly all of them went through major changes in their social and familial relationships as well as worries about the future.

Noman and Yasir (2022) carried out a research on what parents actually need in order to raise their IDD Child. The purpose of the study was to identify the sociodemographic factors that were related to the needs of parents of children with IDD. Using non-probability sampling, 123 parents of IDD children were purposefully chosen for such cross-sectional study. The validity of the questionnaire was demonstrated to experts after a pilot study established its reliability. There were fifteen items for cognitive needs, twelve for material needs, thirteen for social needs, and eight for emotional needs in the questionnaire. Interviews were used to gather data. Inferential and descriptive statistics were employed to analyze it. The results showed that, among those parents, 82.9% had high levels of cognitive needs, 65% had high levels of material needs, 75.6% had high levels of social needs, and 52.8% had high levels of moderate needs. There were variations in the emotional needs of parents based on the age of their IDD children as well as emotional, cognitive, social, and material needs based on the severity of IDD. It was observed that the material needs of parents of IDD children were the mostly required need, then there was cognitive needs, followed by social and emotional needs.

Kruithof, Olsman, Nieuwenhuijse, and Willems (2022) conducted a study about the concerns of parents about their child with profound IDD outliving them. The study was qualitative in nature. In order to investigate parents' worries about their child outliving them, they spoke with 27 parents of IDD children and then thematically analysed those data. The findings indicated that 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. In addition to adding to their worries, parents' uncertainty about who would take on their parental responsibilities in the future occasionally left them feeling hopeless. The study shed light on the type and seriousness of worries held by parents. It would be easier to address future care and gaps in support services for IDD individuals if parents divided their thoughts and worries into roles.

Myers, Mackintosh, and Goin-Kochel (2009) also explored in their study the experiences of parents for raising a child diagnosed with Autism Spectrum. 493 parents having a child with Autism Spectrum in the US and other five countries completed an online questionnaire with an open-ended response to the question of how their child with ASD affected their life as well as the life of their family members. The researcher used qualitative content analysis. The study discovered fifteen negative themes as well as nine positive themes. The five subthemes that were identified were stress or anxiety, behaviour of the child, the parents' personal and professional lives, their marriages, effect on the entire family, and social segregation. The combination of positive and negative themes was seen as a dialectical perspective on finding purposeful meaning of life while also admitting the challenges and stresses of raising a child diagnosed with ASD.

Dumas, Wolf, Fisman, and Culligan (1991) conducted a study entitled "Parenting Stress, Child Behavior Problems, and Dysphoria in Parents of Children with Autism, Down Syndrome, Behavior Disorders, and Normal Development." The study aimed to measure the differences in the feedback given by parents about dysphoria, parenting stress, and behavioural issues found in children. The sample was made up of 150 families having ASD children, behaviour disorders, Down syndrome or normally developed children. The study measured the behavioural issues in child with the help of Eyberg Child Behavior Inventory, stress with the help of Parenting Stress Index, and dysphoria with the Beck Depression Inventory. According to the findings, parents of children with behavioural issues or ASD reported statistically higher levels of stress than parents of children in other groups. Parents of children with behavioural issues stated that compared to other children, their child's behavioural issues were more severe. Additionally, the results showed that mothers of ASD children and children with behavioural disorders had higher levels of dysphoria than mothers of other group’s children.

D**hoot (1992)** in her doctoral dissertation examined what were the impacts that early intervention had, on IDD children. The term "early intervention" refers to a broad range of training, educational, therapeutic, and experimental practices as well as providing supportive experiences. The study compared the developmental outcomes of 25 IDD children who received early intervention versus those who did not. Different therapies were given to the children of the experimental group in individual as well as in a group setting according to his need for the period of 2 years. Parents were also trained to carry out the same programme at home. The same tests were used for re-evaluation of children of the experimental as well as the controlled group after one year and at the end of 2 years of period. Overall, majority of children in the present study made progress. It helped explain why IDD children developed during the crucial developmental stage just like normal children did, albeit more slowly. However children of the experimental group, due to early training reflected the better outcome not only in mental but also in social development comparing to the those who didn’t receive intervention (Control group). The overall results showed that, 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.

Gilmore and Cuskelly (2012) explored self-efficacy along with parenting satisfaction of mothers who had children suffering from Down Syndrome. In the initial phase of the research, the group being studied comprised twenty-five mothers of children (4-6 years) suffering from down syndrome, and then H-15 years at the second phase of the study. The results showed that while mothers' contentment with raising their children grew over time, their self-efficacy remained unchanged. The findings revealed that 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.

Stelter (2015) conducted a study to understand how parents having an IDD child perceived their life. The study did sampling of 65 fathers and 87 mothers of an IDD child. The findings showed, 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 and the manner of performing the role as a parent.

Jeong and Seo (2016) conducted a study to verify the relationship among parenting stress, self-esteem and support from society when mothers have an IDD child. The study was a survey study. Sample consisted of 250 mothers having IDD children and they were sent a questionnaire to answer. The findings indicated that 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.

Badu (2016) conducted a study to look into the experiences of parents of IDD children. The researcher took in-depth interviews from 20 parents of IDD children (4-15 years age) who resided in the Ashanti Region of Ghana. Qualitative content analysis were done after data collection. The findings stated that parents of IDD children faced difficulties taking care of their IDD children because of negative outlook associated for having IDD children in their life. The study also found that managing behavioural challenges of IDD children and financial costs were the major sources of stressors for parents.

Misura and Memisevic (2017) studied about the lifestyle of parents of IDD children. The study not only examined the impact of educational qualification but also studied how gender impacted on the quality lifestyle of these parents. Fifty parents of IDD children as well as fifty parents of children without IDD (control group) made up the sample. Family Quality of Life Survey was used to measure the quality of life of those parents. The findings revealed that a statistically marked major difference was there between the perceived lifestyle of parents of IDD children and parents of normal children.

Fourie and Roux (2017) conducted a study in a special needs class to investigate the support needs of parents who had children with mild IDD. A questionnaire with open-ended questions was used to gather qualitative data. Those parents participated in in-depth interviews. The researchers did a thematic analysis of the data. The findings indicated that parents needed an intense support from other parents, as well as, from the teachers. Parents were extremely confused about how the special class was functioned to which their children had been admitted. 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.

Jalan et. al. (2017) conducted a study in order to examine how behavioural issues in individuals with IDD correlate with degree of severity, sexuality and age. The investigation covered 70 instances of IDD with behavioural issues that were reported to the Nepalgunj Medical College between the month of March in 2013 and February in 2015. The findings showed that disobeying was more common in 22.73% mild IDD cases, 19.15% moderate IDD, 16.67% severe group. When it comes to sex, males were more likely to disobey than females were to physically harm others. Results showed that parents wanted assistance primarily for dealing with issues related to disobedience, unusual behaviour, and the then issues related to physical harm to other people.

Masulani, Kauye, Gladstone, and Mathanga (2018) conducted their research in order to ascertain the risk factors and frequencies of psychological distress among Malawian parents of IDD children. The research was a cross-sectional, quantitative study. It took place in the first two months of 2015. From two disability clinics, 170 fathers and mothers of IDD children were chosen at random. In the study, parents' psychological as well as emotional distress were evaluated using the Self-Reporting Questionnaire. The findings indicated that psychological as well as emotional distress had been expressed by 41.2% of all parents. The study also showed that among parents of IDD children, no source of emotional support strongly predicted psychological distress.

Sheldon, Oliver, and Yashar (2020) carried out a qualitative investigation focusing on fathers' points of view to examine the benefits and difficulties of raising a child who had Down syndrome. 175 fathers who had children suffering from Down syndrome, made up the sample. Those fathers were asked open-ended questions. In the study, inductive content analysis was conducted. The results showed that rewards were mainly the strong father and child bond and a loving child. The findings also indicated that fathers rarely reported financial stress or the negative behaviours of their child. Many fathers reported speech problems faced by their children.

Davenport and Zolnikov (2021) conducted their research to investigate psychological implications in parents of IDD children. The study was phenomenological qualitative in nature. It was conducted by using 25 semi-structured interviews of parents having 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. The findings also indicated that parents experienced mild cases of feelings of compassion fatigue as a result of raising their offspring with IDD.

Indriasari (2022) studied the effects on anxiety and endurance in mothers of IDD children during COVID-19 period. It was a cross sectional study. Mothers having an IDD child attending special schools in Indonesia were the sample. Purposive sampling was followed. 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.

Ahmad, Nazli, and Chavan (2022) conducted a study to find out how depressed the parents were and how psychosocially connected they were with their IDD children. This cross-sectional study was carried out at NCS University in Pakistan, at a rehabilitation centre. There were 184 parents in the sample. Beck's depression inventory scale was used to evaluate the depression level of the parents. The results demonstrated the increased affect and depression experienced by parents of IDD children. The most significant factor influencing the mental as well the emotional well-being of parents of IDD children was financial difficulties. The study also revealed that single mothers having IDD children were found to be more depressed than mothers living with their spouses.

Rios and Burke (2023) conducted a study entitled "Exploring correlates among Latino/a parents of young children with intellectual and developmental disabilities". This study set out to investigate the relationships among empowerment, anxiety, disability type in the child, and special education knowledge in parents of IDD children. 61 Latino/a parents were chosen. The results showed a powerful positive link between parents' knowledge about special education and their empowerment. The results also showed that parents, due to having an autistic children, reported much higher levels of anxiety and also knowledge about special education.

Abdalrazek (2023) conducted a study to identify parenting attitudes towards their Intellectually and Developmentally Disabled children and the relationship to three variables- gender of the child, kinship of father and mother, and parent's education level. 29 fathers and 31 mothers of IDD children were the sample. Questionnaires and forms were sent to those parents. The researcher used the measure of parental attitudes towards mental retardation (prepared by Al-Lahami, 1984). Data were analysed statistically. The findings revealed, there was a high positive parental attitudes towards their IDD children. Most of the parental attitudes were initially characterized by the discrimination between the IDD child and his or her non-disabled siblings.

2.3. Studies Conducted in India

Bhattacharyya, Ghoshal, and Sanyal (2015) conducted their study on “Magnitude of problem of persons having intellectual disability its impact on parents and their unmet needs in Indian subcontinent”. The objective of the study was to examine the disability status of IDD persons as well as the nature and to what extent it impacts their parents. Individuals with intellectual disabilities do not comprise homogenous groups. Their unfulfilled needs and the effect on parents as caregivers also varies, particularly with shifting racial, socioeconomic, and cultural contexts. In the study, the authors compared The clinico-demographic profile of 102 intellectually disabled and intellectually average children and their caregivers. The NIMH-DIS scale was used to determine the impact of disability. Results showed, 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. The parents' relationship domains did not differ from one another. Mothers exhibited greater tolerance, sensitivity, and empathy. Mothers also shown greater patience and compassion. While the effects on fathers were more pronounced in the areas of finances and embarrassment/ridicule, the effects on mothers were more pronounced in the areas of physical care, health, and specific thoughts. The severity of the condition and its effects on parents as caregivers affect the requirement for rehabilitation. The development of an individualised treatment plan for them and their parents might be aided by conducting an appropriate assessment and identifying unmet demands.

Chhotaray (2020) studied the various impacts that IDD children and their disability had on their parents’ life. The study did a comparison of the effects on both parents of IDD child. It was seen in the results that, while both parents were adversely impacted by their child's disability, mothers were heavily impacted. These findings pointed to the importance of maternal caregiving and influences of culture, that could worsen the impact of disabilities and cause distress for mothers of disabled children.

Vijila and Sreelatha (2022) attempted to examine how well parents of IDD children coped with stress. 200 parents of IDD children enrolled in various special schools situated in Kanniyakumari district, made up the sample. The Stress Coping Ability scale was employed by the researcher as a means of data collection in their normative survey. The result showed major differences in the stress coping ability of fathers as well as mothers of IDD children. The result revealed that almost 60% parents of IDD children had moderate stress coping ability. Therefore the study concluded that stress coping ability of those parents might be improved; and health professionals and counsellors could provide strategies to improve the mental health of those parents.

Jubina Bency, John, Navya, and Saju (2017) did a qualitative investigation to evaluate the parenting practices, attitudes, and knowledge of parents of IDD children. It was carried out in some special education schools in Thrissur, Kerala. Parents of IDD children between 5 to 15 years, made up the sample. The KAP questionnaire was used in the study. As per the results, parent's social and economical status, level of education, and employment- all significantly influenced the way they raised their children, which improved the development of the child. According to the study, mothers who had a higher occupations possessed greater amounts of knowledge than mothers with lower occupations. The association between the two groups was found to have statistical significance. The knowledge level among mothers who had higher educational was found to have high statistical significance. Although no major notable difference was there in the knowledge level between parents belonged to nuclear families and those to joint families, the parents in the former showed a moderate level of knowledge. Compared to parents of consecutive birth orders, parents who had an IDD children in their first birth showed a higher knowledge level. Although parents of Idd children in second birth showed a high moderate knowledge level, there was no significant correlation.

Purty and Singh (2018) conducted a study to ascertain the level of knowledge among caregivers of IDD children regarding various aspects of IDD. They claimed that very little research had been done on parents' awareness and knowledge of IDD. They performed a cross-sectional survey in a hospital setting at RINPAS, Ranchi. 100 caregivers of IDD children were chosen purposefully for the study. NIMH, GEM Questionnaire by Reeta Peshawaria and GHQ-12 questionnaire were used to measure the awareness and knowledge of IDD among parents. The findings indicated that 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 Additional findings indicated that parents from non-urban areas were less knowledgeable about the causes and contributing factors to IDD.

Shetty and Menezes (2013) conducted a study to explore the problems and issues that were faced by parents of IDD in Mangalore, India. The following primary objectives were established for the study: 1. to evaluate parents' knowledge of IDD; 2. to investigate the psycho-social and financial issues that parents of IDD kids face; and 3. to offer better strategies for managing those children. Fifty parents of IDD children participated in the study. The researcher took interviews with the help of interview schedules. The findings showed that 50% of respondents from non-urban localities thought that their child's condition was brought on by the evil eye, 16.67% thought that the condition was something the mother had developed during her pregnancy (some of them felt this way because they were taught that the condition resulted from the fetus not developing properly during pregnancy), 5.56% thought that the condition was hereditary, meaning that sometimes it is caused by abnormal genes got in heredity from parents, and 27.77% of rural respondents thought that the condition was caused by an injury sustained during childbirth. In semi-urban localities, 60.57% parents said that having an IDD child made it difficult for them to go out for social interaction or family timing, and 45.45% parents in urban localities said that they felt uncomfortable going out with an IDD child. As compared to normal child, they believed that taking the child out had a significant impact on their status in the society. However, the majority of parents, 54.45% from urban and 39.43% from semi-urban localities, felt that having an IDD child in the family had no impact whatsoever on the quality of their life.

Kapil and Selvan (2017), in their research, tried to determine the level of awareness among parents having IDD children related to the medical and etiological factors of IDD. 60 parents of IDD children made up the sample. Self made tool comprising of 30 items were used by the researchers. The findings indicated, 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.

Khatib and Khatib (2014) conducted a study in order to understand parents' knowledge about IDD and the importance of special schools. Children with IDD were therefore specifically chosen from special schools located in Hubli and Dharwad in Karnataka. For the purpose of testing their knowledge, sixty mothers of IDD kid were chosen at random. Peshwaria and Venkatesan's NIMH-GEM Questionnaire was used to measure their knowledge. Karl Pearson's correlation coefficient analysis was used to test the relationship between the age of mother, social and economical status, and parents' education as well as knowledge. The findings showed that 88.33% mothers lacked knowledge about disabilities. Although some parents were aware of IDD but they lacked sufficient knowledge about the reasons behind the problematic behaviours and how to raise their IDD kids. Mothers (66.67%) believed that special schools helped their children developing socially (75%) and controlling their problem behaviours (60%) as well as help improving their abilities and discipline (75%). The survey also showed that 71.67% of mothers desired training in order to properly care for their children with disabilities. The study came to the conclusion that mothers' socioeconomic status might be raised and their knowledge could be enhanced by providing them with training. Counselling the parents might give them information about their child's disability and special education needs.

Hameed (2021) conducted his research on "Parents having Intellectually Disabled Children: A Systematic review of Quality of Life and Mental wellbeing". The primary objective of the study was to recognize the lifestyle of parents, the intervention strategies provided to them as primary caregivers of IDD children; as well as, to investigate their opinions on raising an IDD child, taking into account the child's formative years, available resources, and potential outcomes. After utilising a variety of survey methods the researcher comes to a conclusion that 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. The main focus of support should be on services related to social care, monetary help, and easy availability of services related to health care. Interventions focused on increasing hope, improving mental health, and anxiety management were essential and what parents of IDD children most urgently required. Considerations regarding this population's economic situation and availability in the future must be made when designing interventions.

Rajan and John (2017) studied on "Resilience and impact of children's intellectual disability on Indian parents". The concept of parental resilience is becoming more popular as a means of addressing parents' natural capacity in order to withstand the strain that may arise from raising a nIDD child. The current study examined parental resiliency and its connection to the effects of a child's disability. NIMH Disability Impact Scale and Connor Davidson Resilience Scale were used to evaluate 121 parents in total. The results showed that raising an IDD child presented both pleasant and unpleasant experiences for the parents. Their evaluation of the kid's health had a big impact on their resiliency. Positive attitudes toward the child's handicap served as a protective factor, while negative ones served as a risk factor for resilience. The results were particularly significant for developing treatments for families of IDD people.

Verma and Kishore (2009) conducted a research in order to understand the combined needs of both parents of IDD, taking into account factors such as sex, age and severity of the child's disability. 30 parents were taken as sample who had a child with IDD. The NIMH Family Needs Schedule was used to measure their needs. The findings showed, parents’ needs differed remarkably. 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.

Sahay, Prakash, Khaique, and Kumar (2013) had studied on “Parents of Intellectually Disabled Children: A Study of Their Needs and Expectations”. The goal of the study was to concentrate on familial requirements from the viewpoint of parents of children with intellectual disabilities. Forty-five parents of IDD children receiving medical treatment at NIMH, New Delhi, were examined. IDD Children with below 70 IQ were included in it. The needs of parents of IDD children were measured using The Family Needs Survey Scale, developed by Bailey and Simeonsson. The scale covered seven domains: family, childcare services, community amenities, monetary requirements, information and support, professional and social support, and explaining to others. This research provides an awareness of parents ‘needs from their perspectives and their description of current strengths and gaps in the systeml. Individual in-person interviews by using a semi-structured interview Schedule were conducted by the researchers. The parents were asked about their views of several needs. The study did Descriptive data analyses and described sample characteristics, the prevalence of support needs and level of met need using the SPSS software.Findings suggested that parents referred to strong needs about information of current and future service available in society and the community (88.7%) which is followed by basic expenses (82.7%), teaching strategies and therapy (80%), day care services (77.8%).

Wagh and Ganaie (2014) had conducted “A Study on Parental Attitude and Needs of the Parents Having Children with Intellectual Disability.”. The purpose of the current study was to evaluate and comprehend the needs and attitudes of parents of children with intellectual disabilities. The sample included thirty parents (both father and mother) from the general services of the National Institute for the Mentally Handicapped, Secunderabad. The evaluation was carried out using “A Scale to measure, parental attitude towards mental retardation (Rangswami, 1986) and NIMH-FAMNS (Parents) to measure needs of the parents”. The researcher analysed the data for the current study by using SPSS 17.0. Calculations included mean, S.D., independent "t" test, ANOVA, and Pearson correlation. The findings of the study showed that having a kid with a disability caused their parents to have a variety of needs like- needs pertaining to the condition of the child, needs pertaining to the management of the children, needs pertaining to the facilitation of interaction, services, emotional and social needs, physical supports, financial support, family relationship, future planning, and needs pertaining to government benefits and legislation of the parents having children with intellectual disabilities. These needs can change depending on the type of disability and the parenting style, one of which is attitude. The study concluded that needs and attitudes were interconnected; when parents had a favourable attitude towards their kids with IDD, they showed greater needs and care. In this study, parents of children with moderate mental retardation (IDD) exhibited higher levels of optimism than those whose children had mild or severe level of IDD.

Mamta and Punia (2003) analysed the parental knowledge regarding mental retardation (Intellectual and Developmental Disabilities) on the basis of background of residential area and socioeconomic status. The data were collected from mothers of severely mentally retarded (IDD) and moderately mentally retarded (IDD) children, 30 from each category, by using self-structured and pre-tested interview schedule and knowledge inventory. The results indicated that 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.

Vijayarani, Balamurgan, and Kasthuri(2016) conducted a study to assess the level of knowledge of family caregivers towards Mentally Challenged (now IDD) Children in selected Institution of Bangalore. The study was descriptive in nature. The mean and mean percentages were calculated to assess the level of knowledge. Result showed that the mean knowledge score (39.33%) showed that they had inadequate knowledge. Majority of 78% of the family caregivers had inadequate knowledge, 20% had moderately adequate knowledge and only 2% of the family caregivers had adequate knowledge. The study threw light on the importance of the need of empowerment of the family caregivers with adequate and appropriate information on the trend of development of the mentally challenged child and to know-how of managing developmental delays so that they could provide suitable environment for their care and development.

Mushtaq, Inam, and Abiodullah (2015) conducted a study on attitudes of parents of children with intellectual disabilities, with regard to the management of problematic behaviour of their children. The study was designed to understand the a attitudes of parents of children with intellectual disabilities, with regard to the management of problematic behaviour of their children, and to identify whether the mothers or the fathers had more positive attitudes. A structured interview schedule was developed. Convenience sampling was used to select 74 parents (30 fathers and 44 mothers) of children with intellectual disability. The data was analysed using descriptive and inferential statistics. Indications were that parents of children with intellectual disability had positive attitudes towards 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.

Mohammad and Osman (2015) studied on “Parental Attitudes Towards Children with Mental Retardation: Across Sectional Study from NGOs in Northern India”. The objective of the study was to explore the attitude of the parents towards their children with mental retardation (now IDD). The study applied a 4x2x2 factorial research design. Samples included 192 parents having children with IDD. Parental Attitude scale developed by Rangaswamy was used in the study. The result showed that there was a parental negative attitude towards children with mental retardation (IDD), and there was a positive correlation of overprotection with education and future, home management and total attitude. The study concluded that there was a parental negative attitude towards children with mental retardation which is highly on home management and lowest on acceptance.

Chourasiya, Baghel, Kale, and Verma (2018) conducted a cross-sectional study on stress perceived by families of mentally challenged children enrolled in special schools of a city of central India”. It was noticed that, 47.97% of fathers and 68% of mothers are in the age group of 30-40 years. The severity of retardation was mild in 36 children, moderate in 46 children while 20 had severe retardation, 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. (67.3%) nuclear families show mild stress while only 22 (52.3%) joint families show mild stress.

Behari (1991) studied the attitudes of mothers of mentally retarded boys towards 23 areas of child rearing as influenced by their strata and education. A sample study of 30 uneducated, low class mothers were matched with those of the mothers of well- educated upper middle class. Their results indicated that the attitudes of educated mothers were significantly different from those uneducated mothers in about seven areas of child rearing practices namely marital conflict, rejection of home making role, intrusiveness, approval of activity and equalitarianism. Hence, it was concluded that it is not the strata and the education per se, which is important in child rearing attitudes, but other psychological variables also play crucial role.

Rose, Nelson, and Hardiman (2016) conducted a study to assess the relationships between maternal stress, challenging behaviour of intellectual disabled children and parental cognitions and specifically whether maternal cognitions mediated the effect of challenging behaviour on parenting stress. The study included 46 mothers of children and young adults with ID (IDD) as sample. The Questionnaire was used in the study which included questions related to the child's challenging behaviour, maternal cognitions and stress. Results indicated significant correlations between challenging behaviour and maternal stress. The overall mediation models for aggression and self-injurious behaviour were significant.

Smith, Romski, Sevcik, Adamson, and Barker(2014) conducted a study to examine differences in parental stress and parental perceptions of language development among parents having children with Down syndrome and Other Developmental Disabilities. The samples included 29 parents of young children having Down syndrome and 82 parents of children having other Developmental Disabilities. The result of the study showed lower levels of overall stress, stress related to the child, and stress related to parent-child interaction reported by the parents having children with Down Syndrome. Despite the fact that children in both groups showed similar language skills, the parents of children with Down Syndrome perceived their child’s communication difficulties as less severe. The parents of children in other group reported about feeling successful in their ability to influence their child’s communication development.

Upadhyay and Havalappanavar (2007) conducted a study to investigate the support of spouses and stress levels among the parents of mentally retard (Intellectually and Developmentally Disabled) children. They compared the stress levels of widowed and widower parents to those of families with both parents alive. Seventy-seven single parents (Fifty-eight widows and nineteen widowers) were compared to seventy-seven families (matched groups) where both parents (father and mother) were alive. The results of the study showed that widow and widower single parents had significantly different stress levels in all four stress areas: care, emotional stress, financial stress, and social stress. Widow and widower had similar levels of care stress, but there was a significant difference in total stress. The stress level of single parent families with mentally retard (Intellectually and Developmentally Disabled) children was higher than that of families with both parents alive. The overall level of emotional, social, and financial distress experienced by widows was significantly greater than the level of care stress experienced by widowers.

Vidhya and Raju (2007) studied the level of adjustment and attitude of parents of children with mental retardation with a sample consists of 50 parents in the age group of 25-50 yrs (either mother or father) of children diagnosed as mentally retarded through an Adjustment Inventory, Scale of

Parental Attitude Towards Mental Retardates, and a Personal Data Sheet. Subjects were grouped on the basis of Religion, Education, Locality, and Income. The results indicated that 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 and parental attitude.

Gupta, Mehrotra, and Mehrotra (2012) noticed that female sex of the child was associated with higher stress related to failure of the child to meet parent’s expectations and to satisfy the parents in their parenting role. Parents engaged in more lucrative and prestigious occupations had more stress than parents engaged in less prestigious and lucrative occupations irrespective of their income. Many parents reported receiving little support from their extended families in taking care of their child. Religion was found to be a common coping resource used by the parents. Higher parenting stress in parents of girls raises the possibility of abuse and neglect. Little support from informal family resources underscores the need for developing formal resources for supporting the parents.

Vivian (2006) studied the parental stress and psychological distress among parents of children with mental retardation (Intellectual and Developmental Disabilities). He examined the relative contributions of child characteristics, parents' socio-demographics, and family environment to parental stress and psychological distress. His results indicate that the model containing all three predictor blocks, child characteristics, parents' socio-demographics, and family environment, accounted for 36.3% and 22.5% of parental stress and parents' psychiatric symptomatology variance, respectively. The age of the child was significantly associated with parents' feelings of distress and psychiatric symptom status, and parental stress was less when the child was older. Parents reported more psychiatric symptomatology when the child showed a high level of dysfunction. Lower socioeconomic level was associated with greater symptom rates of cognitive disturbance, depression, anxiety, and despair among parents.

Singh & Nizamie (2023) conducted a study to assess and compare the behaviour problems and health coping strategies among parents children with intellectual disability and functional psychosis. This study was a cross-sectional hospital based study. The study samples were selected through purposive sampling technique. Results showed that parents of children and adolescents with functional psychosis reported (20.62) higher mean score in this domain 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 children and adolescents with intellectual disability.

Bunga, Manchala, Tondehal, and Shankar (2020) conducted their research to examine the effect of disabilities and nature of parent and child relationships when raising an IDD kid. The findings revealed that 56.63% of parents had a disability impact on the areas of DIS linked to maintaining social relationships with friends and neighbours because of social restrictions, financial difficulties (58.87%), loss of the support from the relatives and the in-laws, and physical care of the kid. The effect of a disability on physical care as well as certain negative emotions increased with the severity of IDD. The majority of those parents (71.72%) said that their IDD child did never cause any humiliation. Positive effects included increased patience and tolerance, according to 67.3% of the parents. According to the research, 67.3% of the parents of the IDD children said that their children had a more beneficial influence than a negative one. This suggested that having a disabled child in the family does not always have a negative outcome or represent poor luck. Increased self-efficacy, parental happiness, and overall family contentment with life can all be beneficial effects in many families, enabling parents to give the required care and support and manage the situation more tactfully.

Sharma, Singh, Murthi, Chatterjee, and Rakkar (2021) conducted a study in order to investigate the psychosocial correlates of anxiety and depression in parents of children with intellectual and developmental disabilities.The goal was to find out how common depression and anxiety were among industrial workers who had children with IDD, as well as to investigate any variations in these conditions between the primary caregivers and the other parents. The study, a cross-sectional observational one, was carried out in a Maharashtra tertiary care multispeciality hospital. The research looked at 99 parents whose kids and teenagers had developmental and intellectual disabilities. The assessment tool utilized was the Hospital Anxiety and Depression Scale (HADS). The findings demonstrated that 66.7% of fathers and 94% of mothers of children with IDD experienced symptoms of depression or anxiety, or both. Additionally, the study found that 91.8% of mothers had anxiety-related scores, 66.3% had depression-related scores, and 64.3% had both depression and anxiety-related scores. Fathers scored suggestively for anxiety in 57.6% of cases, depression in 35.4%, and both in 26.3% of cases. The results showed a significant correlation (P-value <0.05) between the father's age and the child's medical co-morbidities and his anxiety and depression scores.

Merla & Kumar (2021) looked at the anxiety, stress, and depression levels of parents of IDD children. A random selection of 80 parents, 40 of whom were mothers and 40 of whom were fathers, was done in Hyderabad, India. According to research, parents of children with intellectual disabilities—both mothers and fathers—experienced seriously marked levels of stress, anxiety, and depression. Based on statistical analysis of the data, it was concluded that there was no apparent distinction between the levels of depression, stress, and anxiety experienced by mothers and fathers; these conditions were persistent in both genders. Anxiety, stress, and depression were related; if one is present in parents, the two others must appear as well.

Majumder and Chakraborty (2021) studied how parents of IDD children coped with stress. In this study, parents of one IDD child, two kids (one diagnosed with IDD and one without having any disability), and a control group (with one or two children without any disability) were asked to compare their perceived levels of life stress and coping strategies. The observations showed that the parent groups differed in how they perceived their level of stress in life and how they dealt with it. One important factor that was mentioned was gender. This implies, parents of IDD children felt more stress in their lives than parents of children without disabilities of any kind.

Majumder, Pereira, and Fernandes (2005) carried out a research related to stress and anxiety in parent who had children with Mental Retardation (now IDD). The three major aims of the study were to: 1. Determine whether the perceived stress levels of the two parents of IDD children differ; 2. Investigate whether the parents of IDD children experience these stresses more frequently than the parents of children without IDD; and 3. Look for any relationships between the parents' anxiety levels and the perceived stress levels of those parents. This study was conducted in a hospital that provides tertiary care psychiatry. The sample included 180 parents of IDD children. The 180 participants in the study were split up into three groups: Sixty parents made up Group A, whose children suffered from profound to moderate IDD; sixty parents made up Group B, whose children suffered from mild to borderline IDD; and sixty parents made up Group C, the control group, whose children had normal intelligence. The Hamilton Anxiety Rating Scale (HARS) and the Family Interview for Stress and Coping (FISC) in Mental Retardation were used to assess each parent. Results showed that, compared to parents in groups B and C, parents in group A experienced stressors more frequently and experienced higher levels of anxiety. According to the findings of the study, parents' anxiety levels and stressors were positively correlated. Compared to the parents in the control group, parents in groups A and B were more susceptible to stress due to a variety of complex reasons.

Upreti and Singh (2017) conducted research in order to examine the variations in the kind and degree of coping mechanisms used by parents of children with intellectual disabilities across a range of educational backgrounds. The study found that parents' perceived educational attainment had an impact on their coping strategies. Mothers who had completed more education had lower misconceptions, better level of awareness of their child's condition, higher expectation for their children, positive outlook toward their child and child management, and positive training-specific parenting practices. In a similar vein, fathers who had completed more education also reported having superior coping mechanisms in these areas.

Francina, Tintu, and Ivan (2018) studied the difficulties faced by parents of two IDD children. The purpose of the study was to evaluate psychosocial issues that parents of multiple children with IDD in Mangalapuram Panchayath, Trivandrum District, Kerala, faced. The emotional flexibility of parents, the function of support networks, and the safety measures the family adopted after their first child was born, were among the psychosocial factors taken into account for this qualitative study. Data were gathered from five of the fifteen cases that Mangalapuram Panchayath had identified. Compared with families whose children are typically developing, the challenges faced by the families of two disabled children indicated multiple levels of stress. These families dealt with a variety of issues that impact their quality of life, from financial to social, psychological, and physical issues.

Santosh (2016) carried out a research to identify the stressors that could jeopardize the adaptability of parents of children with IDD. 50 parents of IDD children from various panchayats in the districts of Calicut, Kannur, and Wayanad in the Indian state of Kerala made up the sample. The parents of those IDD children showed a negative correlation between their resilience and extra-familial stress. The findings also showed that 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.

Gull (2015) made an effort to investigate the disparities in psychological health and hope between parents who had physically and intellectually disabled children. It also investigated if hope and psychological health were significantly correlated. 200 parents with differently abled children between the ages of 35 and 45 made up the sample (100 parents with physically challenged children and 100 parents with intellectually disabled children). The results indicated that 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. Furthermore, the results indicated a strong, favourable, and statistically significant correlation between psychological well-being and hope among parents of disabled children.

Sekar and Gopalakrishnan (2015) conducted their study on the emotional and the psychological conditions of parents of children with IDD. This primary objectives of the current study were to have better understanding of mental as well as emotional health of parents of IDD children and to demonstrate how parents generally perceive this condition in their children. The anxieties of parents whose daughter has mental illness are exacerbated. Owing to these anxieties, the findings showed that parents had considered having their daughter's reproductive organs removed and had admitted to hiding their identity in public. The study concluded that parents must receive basic medical training and education about their daughters' reproductive rights in order to prevent mismanaging their child's health.

Meek (1981) asserted that when parents learn their child has an Intellectual and Developmental Disability, they almost always go through a period of intense emotional distress. Working with those parents of children IDD suggested that they frequently had special needs and felt more anxious about their IDD children than those parents who had normal children. These needs might include anything from help adjusting to their child's condition to counselling and direction on how to raise their IDD child. When parents discussed their experiences with their child who had an Intellectual and Developmental Disability, it became clear that professionals frequently had not met their needs, or had only met them on the surface.

Pahantasingh, Krishnan, Pradhan, Samantaray, and Pradhan (2018) carried out a study to evaluate parents' attitudes toward their IDD children, the psychosocial effects of those attitudes, and the relationship between the two.The results of their study showed that parents had an attitude that was 23.34% negative and 70% positive. It also showed that parents had an intermediate positive psychosocial impact of 10%, a severe positive psychosocial impact of 90%, an intermediate negative impact of 86%, and a mild and severe negative psychosocial impact of 7%. Analysis of the data showed a significant positive relationship between parents' attitudes and psychosocial impact, with a r value of 0.18. This implied that a good attitude would have a favourable effect.

Ahmad, Nazli, and Chavan (2022) conducted a study on the parents of children with Intellectual (and Developmental) Disabilities to determine their knowledge, attitudes, and practices regarding sex education. 130 parents of IDD children were taken as sample by using random sampling technique. The researchers used the Awareness on Sexual Education for Parents of Intellectually Challenged Children Scale, developed by Lakshmi and Navya (2014), to assess parents' knowledge, attitudes, and practices. The findings indicated that there were no appreciable differences in parents' knowledge, attitudes, or practices based on their gender. Based on their educational background, parents' attitudes and knowledge differed significantly. Additionally, a significant positive correlation was found between practice and knowledge ($r = 0.233$), knowledge and attitude ($r = 0.453$), and practice and attitude ($r = 0.252$). The study found that 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.

Review Matrix

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)	*Journal of applied research in intellectual disabilities : JARID*	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)	*Journal of consulting and clinical psychology*	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)	*Turkish Online Journal of Qualitative Inquiry*	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)	*African Journal of Disability*	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)	*Theses & Dissertations. 106.* https://digitalcommons.molloy.edu/etd/106	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)	*Health care for women international*	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).	*Crescent Journal of Medical and Biological Sciences*	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)	*USF Tampa Graduate Theses and Dissertations.* https://digitalcommons.usf.edu/etd/4722/	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).	*Autism*	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).	*Polish Sociological Review.*	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)	*American Journal on Mental Retardation*	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).	*International Journal of Caring Sciences*	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).	*Journal of advanced nursing.*	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).	*Revista Inclusiones*	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 Phenomenological Study	Abani, M., Anislag, R., Budiongan, G., Cagape, W., & Paz, C. (2023).	*International Journal of Research Publications (IJRP),*	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).	*American Journal on Mental Retardation*	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 hassels & problem-focused.	Gavidia-Payne, S., & Stoneman, Z. (2006).	*American Journal on Mental Retardation*	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).	*Journal of Intellectual Disabilities*	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).	*SAGE Open*	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).	*Journal of Applied Research in Intellectual Disabilities.*	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., & Chugtai, A. S. (2022).	*Pakistan Journal of Medical and Health Sciences*	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).	*Trauma Care*	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).	*Health SA Gesondheid*	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).	*Journal of Intellectual Disabilities*	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).	*Mental retardation*	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).	*Cognizance Journal of Multidisciplinary Studies*	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).	*Journal of Intellectual & Developmental Disability.*	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).	*Journal of Holistic Nursing and Midwifery*	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).	*Disability & Society*	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).	*British Journal of Learning Disabilities.*	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).	*Journal of Special Education*	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).	*Rehabilitation psychology*	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).	*Journal of Applied Research in Intellectual Disabilities*	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).	*Bangladesh Journal of Medical Science*	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).	*J Psychiatr Res*	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).	*Australian Socal Work*	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).	*Chinese Journal of Clinical Rehabilitation*	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).	*Birat Journal of Health Sciences*	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).	*Asia Pacific Journal of Social Work and Development*	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).	*KHYBER MEDICAL UNIVERSITY JOURNAL*	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).	*Journal of Mental Health Research in Intellectual Disabilities*	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).	*International Journal of Health Sciences*	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)	*Journal of Intellectual & Developmental Disability*	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).	*Research in Autism Spectrum Disorders*	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).	*Exceptionality*	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, SNDT Women’s University. http://hdl.handle.net/10603/119496	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).	*Journal of Family Studies*	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, Ż. (2015).	https://www.diametros.iphils.uj.edu.pl/diametros/article/view/838	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).	*Journal of Korean Clinical Health Science*	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).	*Journal of Social Inclusion*	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).	*Journal of Educational and Social Research*	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).	https://www.researchgate.net/publication/320716749_Supporting_Parents_who_have_children_with_Mild_Intellectual_Disabilities_in_a_Special_Needs_Class_in_Gauteng	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).	*Journal of Nepalgunj Medical College*	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).	*BMC Psychiatry*	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).	*Disability and Rehabilitation*	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).	*Journal of Intellectual Disabilities*	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).	*Jurnal Keperawatan Soedirman*	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).	*Journal Riphah College of Rehabilitation Sciences*.	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).	*Autism research : official journal of the International Society for Autism Research*	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).	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	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).	*Bengal Journal of Psychiatry*	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).	*The International Journal of Indian Psychology*	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).	*International Journal of Health Sciences*	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).	*International Journal of Current Advance Research*	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).	*International Journal of Research in Social Sciences*	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).	*Global Journal of Interdisciplinary Social Science*	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).	*Scholarly Research Journal for Interdisciplinary Studies*	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).	*Karnataka J. Agric Sci*	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).	*IJIRT*	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).	*Journal of intellectual disabilities*	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).	*International journal of rehabilitation research.*	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).	*International Journal of Humanities and Social Science Invention*	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).	*International Journal of Clinical Therapeutics and Diagnosis*	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.).	*Behavioural Management in Rural Development*. 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).	*International Journal of Applied Research*	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).	*Disability, CBR & Inclusive Development*	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).	*Int J Res Health Sci*	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).	*Int J Community Med Public Health*	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).	*Disabilities and Impairments*	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).	*Behavioural and cognitive psychotherapy,*	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., Romski, M., Sevcik, R. A., Adamson, L. B., & Barker, R. M. (2014).	*Family relations*	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).	*Journal of the Indian Academy of Applied Psychology*	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).	*Journal of the Indian Association of Applied Psychology*	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).	*Disability CBR & Inclusive Development*	To determine parenting stress and determinants among parents of children with disablities 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).	*Social Science Medicine*	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).	*IJCAR*	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).	*Indian Journal of Social Psychiatry*	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 IndPsychiatryJ000-6252997 172209.	Sharma, R., Singh, H., Murthi, M., Chatterjee, K., & Rakkar, J. (2021).	*Industrial Psychiatry Journal*	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).	*The International Journal of Indian Psychology*	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).	*Indian Journal of Health and Wellbeing*	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).	*Indian Journal of Psychiatry*	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 Perceived Stress Resulting from having Intellectually Disabled Child: Comparison Across Educational Level of Parents.	Upreti, R., & Singh, R. (2017).	*International Journal of Basic and Applied Agricultural Research*	To examine the variations in the kind and degree of coping mechanisms used by parents of IDD children.	Mothers who had completed more education had 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).	*Artha - Journal of Social Sciences*	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.), *Handbook of Research on Diagnosing, Treating, and Managing Intellectual Disabilities* (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).	*International Journal of Modern Social Sciences*	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 intellectually and developmentally disabled children.	Sekar, N., & Gopalakrishnan, A. (2015).	*International Journal on Disability and Human Development*	To have better understanding of mental as well as emotional health of parents of IDD children.	Parents had considered having their daughter's 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).	*Australian Child and Family Welfare*	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).	*International Journal of Health Sciences and Research*	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).	*Indian Journal of Social Psychiatry*	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.

2.4. 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.

2.5. 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.

2.6. Statement of the 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***

2.7. Operational Definitions of the Key Terns Used

2.7.1. Parents: A person's father or mother.

2.**7.2. 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.

2.**7.3. 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.

2.7.4. Intellectually and Developmentally Disabled Children: Children having notable deficits in intellectual functioning as well in adaptive skills.

2.7.5. 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.

2.7.6. Problem: Something that causes difficulty or that is hard to deal with

2.**7.7. Need:** Something that is required as essential in life.

2.7.8. Gender: Either of the two sexes (male and female)

2.8. 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?

2.9. Objectives

The researcher has proposed the following objectives for the current 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

2.10. Variables

Independendent or Predictor	Dependent
Age, Gender, income, education, occupation, residential background, family type, schooling, level of disability, early intervention therapy, training	Knowledge, Problems and needs of parents of IDD children

2.11. Hypotheses

All the hypotheses are formulated in null form for testing as mentioned below:

H_{01}. There will be no significant mean difference in knowledge of parents about IDD on the basis of their gender
H_{02}. There will be no significant mean difference in knowledge of parents about IDD on the basis of their age

H_{03}. There will be no significant mean difference in knowledge of parents about IDD on the basis of their education

H_{04}. There will be no significant mean difference in knowledge of parents about IDD on the basis of their occupation

H_{05}. There will be no significant mean difference in knowledge of parents about IDD on the basis of their residential background

H_{06}. There will be no significant mean difference in knowledge of parents on the basis of early intervention therapy provided to their IDD children

H_{07}. There will be no significant mean difference in problems faced by the parents on the basis of their gender.

H_{08}. 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_{09}. There will be no significant mean difference in problems faced by the parents on the basis of their income

H_{010}. There will be no significant mean difference in problems faced by the parents on the basis of their residential background

H_{011}. There will be no significant mean difference in problems faced by the parents on the basis of the type of their family

H_{012}. 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_{013}. There will be no significant mean difference in needs of parents on the basis of the gender of their differently abled child.

H_{014}. There will be no significant mean difference in needs of parents on the basis of the level of disability of their children.

H_{015}. There will be no significant mean difference in needs of parents on the basis of their income

H_{016}. There will be no significant mean difference in needs of parents on the basis of their residential background

H_{017}. There will be no significant mean difference in needs of parents on the basis of early intervention therapy provided to their IDD children

H_{018}. There will be no significant mean difference in needs of parents on the basis of the availability of training about management of their child.

2.12. 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.

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CHAPTER - III

RESEARCH METHODOLOGY

3.1. Introduction

The act of conducting research is about adding something new to the field of knowledge to improve it, as well as, to help it grow. Research refers to the pursuit of truth and the truth is sought by investigating, observing, comparing and experimenting. Research aims to seek solutions to the queries by employing scientific procedures. As Kothari (2004) stated,

> “when we talk of research methodology we not only talk of the research methods but also consider the logic behind the methods we use in the context of our research study and explain why we are using a particular method or technique and why we are not using others so that research results are capable of being evaluated either by the researcher himself or by others.”

This chapter talks about how the study was done. It describes the way the study was designed, the methods used, the people studied, the tools and techniques used, and how the data was collected.

3.2. Research Design

Creswell (2014) explains, “Research designs are plans and the procedures for research that span the decisions from broad assumptions to detailed methods of data collection and analysis.”

The research design for this study, as applied by the researcher, involves a combination of different methods, known as the Mixed Method Research design. Mixed Methods are utilized across a variety of fields such as Sociology, Education, Psychology, Nursing and health sciences, and business. As Creswell and Plano Clark (2011) stated, “Mixed methods research is the procedure for collecting, analyzing and mixing both qualitative and quantitative methods in a single study or a series of studies to understand a research problem”.

Mixed method research involves answering not just the "what" questions in a study but also the "how" and "why" questions simultaneously (when the researcher needs to integrate both qualitative and quantitative methods, tools, data, as well as, techniques for data analysis). Hence, mixed methods research is selected by researchers seeking a comprehensive understanding of study variables from diverse perspectives.

Creswell (2015), presented six Mixed Method Research designs, namely “Convergent Parallel Design”, “Explanatory Sequential Mixed Design”, “Exploratory Sequential Mixed Design”, “Embedded Mixed Design”, “Multiphase Mixed Design” and “Transformative Mixed Design”. Mills and Gay (2016) showed three different ways to conduct Mixed Method Research. They are called

“Explanatory Sequential Design”, “Exploratory Sequential Design” and “Convergent Parallel Design”. The researcher has used the Convergent Parallel Design to conduct her current study.

The convergent parallel design (QUAN + QUAL) is also referred to as “integrative” or “concurrent triangulation design”. The researchers in this study place equal emphasis on both qualitative and quantitate data and gathers them simultaneously; afterwards, look at the results to find out what is similar and different between the two sets of data. In this study, the data are gathered at the same time instead of in different studies. When researchers obtain similar results from different methods, they use triangulation as a way to confirm their findings.

As Creswell (2015) stated, there are different ways to demonstrate the comparison, such as transforming one data set to directly compare it with another, or by presenting the qualitative and quantitative results side by side in the discussion section, or by merging them into a single topic-based table. The design is visible in the diagram presented below:

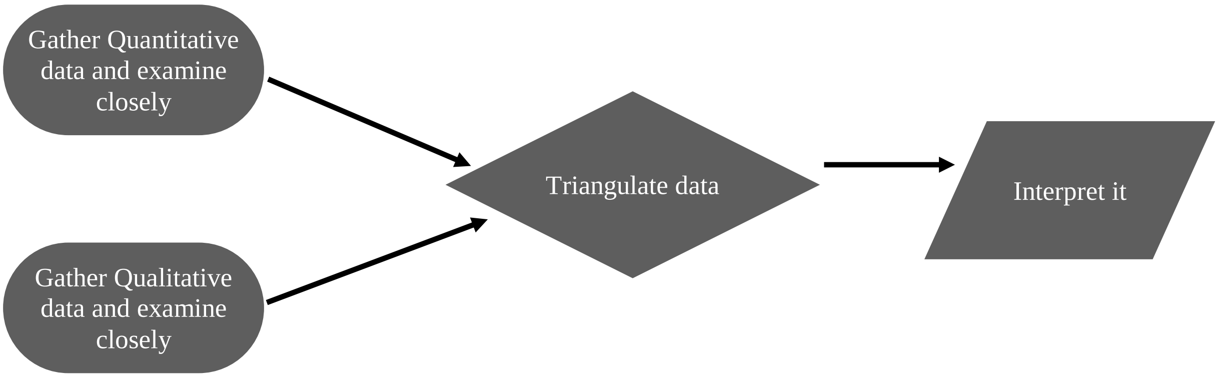

Diagram: Convergent Parallel Design (QUAN+QUAL)

3.3. Method for Data Collection

The researcher used Descriptive Research Method for her study. For quantitative data collection she used Survey method. It has been commonly utilized in the field of education for a long time. Creswell (2014) stated that, in survey research researchers conduct a quantitative survey to a set of individuals to find out information about their mindsets, point of view, behaviours, as well as traits or characteristics. Then the researcher followed Case Study method for qualitative data collection. A case study is a helpful way to study a particular programme, process or person in a thorough and complete way to understand it better. Creswell (2014) defined case study as a method through which researchers deeply study a specific thing, like an event or a group of people, and gather lots of information about it. He also advised the use of case studies to achieve a deep understanding of a particular problem or situation.

3.4. Population and Sample

Best and kahn (2007) stated, “A population is any group of individuals who have one or more characteristics in common that are of interest to the researcher. The population may be all the individuals of a particular type or a more restricted part of that group". The researcher selected West Bengal as the population of her study.

A sample is a subset of a larger population chosen to represent the entire population. It is a smaller version the entire collection or group that it was extracted from. It is a miniature representation of a larger entity. An ideal sample should accurately represent the population and have a size that ensures the reliability of its traits.

The process of sampling entails choosing a small representative sample from a larger population to study and make inferences from. According to Kerlinger (2007) "Sampling is taking any portion of a population or universe as representative of that population or universe".

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.

3.5. 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)
- ii. Parents Problem Inventory (PPI)- (Adopted from Dr. Anju Singh)
- iii. Family Need Schedule (Parents)- (Adopted from Reeta Peshawaria, 1994)

I. **Knowledge Assessment Tool/ Questionnaire :** 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. Validity of the tool was established through content validity. The scale demonstrates well face validity. The draft questionnaire was given to the professionals for selecting the items from the draft tools. After 21 days the first draft questionnaires were again given to same 3 professionals for selecting and considering the items. Reliability of the scale was established by inter-rater reliability method. The reliability coefficient of the scale is 0.79 including internal reliability.

II. Parents Problem Inventory (PPI) : 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.

Areas	**No of Items**
1. Family problem	10
2. Psychological problem	6
3. Physical problem	9
4. social problem	8
5. school and vocational problem	6
6. profession advice problem	4
7. child management problem	6
8. financial problem	5
9. psychosomatic problem	3

Scoring was like if the response was Yes' a score of "2" was given. For 'No’ response a score of "I" was given. So the total score on this inventory ranged from 57-114. The higher the score the greater was the problems of parents with the IDD children. Reliability for Parents Problem Inventory was established by test-retest method. Reliability coefficients were calculated for each area of the problem inventory, they are family problems= 0.781, for psychological problems= 0.73, for physical problems= 0.68, for child management problems= 0.68, for financial problems= 0.81, for vocational problems= 0.77, for social problems=0.66, for psychosomatic problems=0.81 and for professional advice problems= 0.706. The content validity of the test was established by the contemporary method of validation by expert opinion.

III. **Family Need Schedule (parents):** The tool was developed by Peshawaria, Menon, Ganguly, Roy, Pillay and Gupta in 1995. NIMH- FAMNS is a semi structured interview schedule and it is used for the following purposes:

1. To identify needs of the Indian families having individuals with Intellectual and Developmental Disability.
2. To priorities the needs for family intervention.
3. To objectively evaluate family intervention programme.

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.

Areas	**No of Items**
1. Information condition	6
2. Child management	8
3. Facilitating interaction	2

Areas	**No of Items**
4. Services	5
5. Vocational planning	1
6. Sexuality	1
7. Marriage	1
8. Hostel	2
9. Personal-emotional	4
10. Personal-social	2
11. Support-physical	3
12. Financial support	3
13. Family relationship	2
14. Future planning	2
15. Government benefits and legislation	2

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

3.6. 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.

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CHAPTER - IV

DATA ANALYSIS AND INTERPRETATIONS

4.1. Introduction

This chapter deals with the detailed description of data analysis and interpretations. The obtained 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 analysis and interpretations of the results are presented below:

4.2. Analysis of Quantitative Data

4.2.1. Analysis of Mean Score and Testing of Hypotheses through t-Test and ANOVA

Researcher computed t-test and ANOVA for testing hypotheses. All the hypotheses are formulated in null form for testing as mentioned below:

H_{01}. There will be no significant mean difference in knowledge of parents about IDD on the basis of their gender

Table 1. t-Test
Group Statistics

Score

Variable	Group	N	Mean	SD	t value
Gender of Parents	Male	89	16.35	3.012	0.614
	Female	111	16.62	3.222	

The mean value of Table 1 shows that the mother's secured mean value is 16.62 and the father's secured mean value is 16.35. Hence, the above mean values revealed that the mothers have more knowledge than fathers. The obtained t value is 0.614 which is less than the critical value. Hence, the null hypothesis is accepted and it is concluded that there is no significant mean difference in knowledge of parents about IDD on the basis of their gender.

H_{02}. There will be no significant mean difference in knowledge of parents about IDD on the basis of their age

Table 2. Descriptives

Score

Variable	Group	N	Mean	SD
Age	25-34	70	16.19	3.191
	35-44	110	16.95	3.088
	45-54	20	15.15	2.681

Table 2.1. ANOVA

Score

Source of Variation	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	65.192	2	32.596	3.418	0.035
Within Groups	1878.808	197	9.537		
Total	1944.000	199			

P value is significant <0.05

The mean value of Table 2 shows that the mean value of parents in the age group 35-44 is 16.95 which is higher than the mean value of parents in the age group 25-34 (16.19) and parents in the age group 45-54 (15.15). Hence, the above mean values revealed that the parents in the age group of 35-44 have more knowledge than the parents in the age group of 25-34 and 45-54. In the ANOVA test done in Table 2.1, the significance value is 0.035 (i.e., p=0.035), which is below 0.05. Therefore, the null hypotheses is rejected concluding that parent’s age has a high impact on knowledge of parents about IDD. There is a significant mean difference in knowledge of parents about IDD on the basis of their age.

H_{03}. There will be no significant mean difference in knowledge of parents about IDD on the basis of their education

Table 3. Descriptives

Score

Variable	Group	N	Mean	SD
Education	PG	73	18.37	2.348
	UG	34	18.85	2.231
	9-12th	41	15.68	2.055
	Upto 8th Std	52	12.98	1.393

Table 3.1. ANOVA

Score

Source of Variation	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	1114.863	3	371.621	87.848	0.000
Within Groups	829.137	196	4.230		
Total	1944.000	199			

P value is significant <0.05

The mean value of Table 3 shows that the mean value of parents who completed their UG is 18.85 which is higher than the mean value of parents who completed their PG (18.37) and parents who studied upto 9-12th (15.68) and parents who studied upto 8th (12.98). Hence, the above mean values revealed that the parents who completed their UG expressed more knowledge than the parents who did their PG, 9-12th or upto 8th. In the ANOVA test done in Table 3.1, the significance value is 0.000 (i.e., p=0.000), which is much below 0.05. Therefore, the null hypotheses is rejected concluding that parent's education has a high impact on knowledge of parents about IDD. There is a significant mean difference in knowledge of parents about IDD on the basis of their education.

H_{04}. There will be no significant mean difference in knowledge of parents about IDD on the basis of their occupation

Table 4. Descriptives

Score

Variable	Group	N	Mean	SD
Occupation	Govt	62	18.89	1.661
	Private	91	16.08	3.049
	Housewives	47	14.17	2.615

Table 4.1. ANOVA

Score

Source of Variation	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	624.690	2	312.345	46.640	0.000
Within Groups	1319.310	197	6.697		
Total	1944.000	199			

P value is significant <0.05

The mean value of Table 4 shows that the mean value of parents who are employed in govt sectors is 18.89 which is higher than the mean value of parents who worked in private sectors (16.08) and parents who are housewives (14.17). Hence, the above mean values revealed that the parents who are employed in govt sectors showed higher level of knowledge than those who are in private sectors or housewives. In the ANOVA test done in Table 4.1, the significance value is 0.000 (i.e., p=0.000), which is much below 0.05. Therefore, the null hypotheses is rejected concluding that parent's occupation has a high impact on knowledge of parents about IDD. There is a significant mean difference in knowledge of parents about IDD on the basis of their occupation.

H_{05}. There will be no significant mean difference in knowledge of parents about IDD on the basis of their residential background

Table 5. t-Test
Group Statistics

Score

Variable	Group	N	Mean	SD	t value
Residence	Urban	88	18.86	2.018	12.769
	Non-Urban	112	14.64	2.532	

The mean value of Table 5 denoted that the parents who reside in urban area secured 18.86 mean value and the parents residing in non urban area secured mean value of 14.64. Based on the mean value, the parents who reside in urban area have higher knowledge than those who reside in non urban areas. The obtained t value is 12.769. The t value is greater than the critical value. Hence, the null hypothesis is rejected and it is concluded that there is a significant mean difference in knowledge of parents about IDD on the basis of their residential background.

H_{06}. There will be no significant mean difference in knowledge of parents on the basis of early intervention therapy provided to their IDD children

Table 6. t-Test
Group Statistics

Score

Variable	Group	N	Mean	SD	t value
Child Therapy	Yes	104	18.87	1.916	18.111
	No	96	13.94	1.929	

The mean value of Table 6 denoted that the parents whose IDD child was provided with early intervention therapy secured 18.87 mean value and the parents whose IDD child did not get any early intervention therapy secured mean value of 13.94. Based on the mean value, the parents whose IDD child got early intervention therapy expressed more knowledge than those whose IDD child did not get any early intervention therapy. The obtained t value is 18.111. The t value is greater than the critical value. Therefore, the null hypothesis is rejected and it is concluded that there is a significant mean difference in knowledge of parents on the basis of early intervention therapy provided to their IDD children.

H_{07}. There will be no significant mean difference in problems faced by the parents on the basis of their gender

Table 7. t-Test
Group Statistics

Score

Variable	Group	N	Mean	SD	t value
Gender of Parents	Male	93	73.19	6.496	-0.216
	Female	107	73.39	6.504	

The mean value of Table 7 shows that the mother's secured mean value is 73.39 and the father's secured mean value is 73.19. Hence, the above mean values revealed that the mothers faced greater problems than fathers. The obtained t value is 0.216 which is less than the critical value. Hence, the null hypothesis is accepted and it is concluded that there is no significant mean difference in problems faced by the parents on the basis of their gender.

H_{08}. There will be no significant mean difference in problems faced by the parents on the basis of the level of disability of their children

Table 8. t-Test
Group Statistics

Score

Variable	Group	N	Mean	SD	t value
Level of Disability	Mild	110	70.54	6.069	7.541
	Moderate	90	76.68	5.285	

The mean value of Table 8 denoted that the parents having Mild IDD child secured 70.54 mean value and the parents who have Moderate IDD child secured mean value of 76.68. Based on the mean value, the parents who have moderate IDD child faced greater problems than those having mild IDD child. The obtained t value is 7.541. The t value is greater than the critical value. Therefore, the null hypothesis is rejected and it is concluded that there is a significant mean difference in problems faced by the parents on the basis of the level of disability of their children.

H_{09}. There will be no significant mean difference in problems faced by the parents on the basis of their income

Table 9. Descriptives

Score

Variable	Group	N	Mean	SD
Income	10,000/-	65	75.98	5.461
	Below 10,000/-	19	76.16	5.814
	Above 10,000/-	116	71.33	6.444

Table 9.1. ANOVA

Score

Source of Variation	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	1074.937	2	537.469	14.518	0.000
Within Groups	7293.063	197	37.021		
Total	8368.000	199			

P value is significant <0.05

The mean value of Table 9 shows that the mean value of parents earning below Rs. 10,000/- is 76.16 which is higher than the mean value of parents earning Rs. 10,000/- (75.98) and parents earning above Rs. 10,000/- (71.33). Hence, the above mean values revealed that the parents who earn below Rs. 10,000/- faced more problems than the parents who earn Rs. 10,000/- and above. In the ANOVA test done in Table 9.1, the significance value is 0.000 (i.e., p=0.000), which is much below 0.05. Therefore, the null hypotheses is rejected concluding that there is a significant mean difference in problems faced by the parents having IDD child on the basis of their income.

H_{010}. There will be no significant mean difference in problems faced by the parents on the basis of their residential background

Table 10. t-Test

Group Statistics

Score

Variable	Group	N	Mean	SD	t value
Residence	Urban	89	72.53	6.280	1.512
	Non Urban	111	73.92	6.599	

The mean value of Table 10 denoted that the parents who reside in urban area secured 72.53 mean value and the parents residing in non urban area secured mean value of 73.92. Based on the mean value, the parents who reside in the non urban area faced much greater problems than those who reside in the urban areas. The obtained t value is 1.512. The t value is less than the critical value. Therefore, the null hypothesis is accepted and it is concluded that there is no significant mean difference in problems faced by the parents on the basis of their residential background.

H_{011}. There will be no significant mean difference in problems faced by the parents on the basis of the type of their family

Table 11. t-Test
Group Statistics

Score

Variable	Group	N	Mean	SD	t value
Type of Family	Nuclear	115	72.26	6.721	2.676
	Non Nuclear	85	74.71	5.902	

The mean value of Table 11 denoted that the respondents belonging to the nuclear family secured 72.26 mean value and the respondents who belonged to the non nuclear family secured mean value of 74.71. Based on the mean value, the respondents who belong to the non nuclear family faced much greater problems than nuclear family. The obtained t value is 2.676. the t value is greater than the critical value. Therefore, the null hypothesis is rejected and it is concluded that there is a significant mean difference in problems faced by the parents on the basis of the type of their family.

H_{012}. 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

Table 12. t-Test
Group Statistics

Score

Variable	Group	N	Mean	SD	t value
Type of Schooling	Special	100	71.21	6.503	4.804
	Regular	100	75.39	5.780	

The mean value of Table 12 denoted that the parents whose IDD child is admitted to special school secured 71.21 mean value and the parents whose IDD child is admitted to regular school secured mean value of 75.39. Based on the mean value, the parents whose IDD child is admitted to regular schools faced much greater problems than those admitted to special schools. The obtained t value is 4.804. the t value is greater than the critical value. Therefore, the null hypothesis is rejected and it is concluded that there is a significant mean difference in problems faced by the parents on the basis of the type of schooling of their IDD children.

H_{013}. There will be no significant mean difference in problems faced by the parents on the basis of the gender of their disabled child

Table 13. t-Test
Group Statistics

Score

Variable	Group	N	Mean	SD	t value
Gender of child	Male	96	73.78	6.479	1.008
	Female	104	72.86	6.489	

The mean value of Table 13 denoted that the parents having male IDD child is secured 73.78 mean value and the parents who have female IDD child secured mean value of 72.86. Based on the mean value, the parents who have male IDD child faced much greater problems than those having female IDD child. The obtained t value is 1.008. the t value is less than the critical value. Therefore, the null hypothesis is accepted and it is concluded that there is no significant mean difference in problems faced by the parents on the basis of the gender of their disabled child.

H_{014}. There will be no significant mean difference in needs of parents on the basis of the level of disability of their children

Table 14. t-Test
Group Statistics

Score

Variable	Group	N	Mean	SD	t value
Level of Disability	Mild	109	79.20	2.364	0.332
	Moderate	91	79.32	2.603	

The mean value of Table 14 denoted that the parents having Mild IDD child is secured 79.20 mean value and the parents who have Moderate IDD child secured mean value of 79.32. Based on the mean value, the parents who have moderate IDD child expressed greater needs than those having mild IDD child. The obtained t value is 0.332. the t value is less than the critical value. Therefore, the null hypothesis is accepted and it is concluded that there is no significant mean difference in needs of parents on the basis of the level of disability of their children.

H_{015}. There will be no significant mean difference in needs of parents on the basis of their income

Table 15. Descriptives

Score

Variable	Group	N	Mean	SD
Income	10,000/-	65	79.78	2.281
	Below 10,000/-	19	80.68	1.565
	Above 10,000/-	116	78.72	2.549

Table 15.1. ANOVA

Score

Source of Variation	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	89.733	2	44.866	7.862	0.001
Within Groups	1124.262	197	5.707		
Total	1213.995	199			

P value is significant <0.05

The mean value of Table 15 shows that the mean value of parents earning below Rs. 10,000/- is 80.68 which is higher than the mean value of parents earning Rs. 10,000/- (79.78) and parents earning above Rs. 10,000/- (78.72). Hence, the above mean values revealed that the parents who earn below Rs. 10,000/- expressed greater needs than the parents who earn Rs. 10,000/- and above. In the ANOVA test done in Table 15.1, the significance value is 0.001 (i.e., p=0.001), which is below 0.05. Therefore, the null hypotheses is rejected concluding that parent's income has a high impact on the needs expressed by parents having IDD child. There is a significant mean difference in needs of parents having IDD child on the basis of their income.

H_{016}. There will be no significant mean difference in needs of parents on the basis of their residential background

Table 16. t-Test

Group Statistics

Score

Variable	Group	N	Mean	SD	t value
Residence	Urban	89	78.08	2.404	6.665
	Non Urban	111	80.20	2.097	

The mean value of Table 16 denoted that the parents who reside in urban area secured 78.08 mean value and the parents residing in non urban area secured mean value of 80.20. Based on the mean value, the parents who reside in the non urban area expressed greater needs than those who reside in the urban areas. The obtained t value is 6.665. The t value is greater than the critical value. Therefore, the null hypothesis is rejected and it is concluded that there is a significant mean difference in needs of parents on the basis of their residential background.

H_{017}. There will be no significant mean difference in needs of parents on the basis of early intervention therapy provided to their IDD children

Table 17. t-Test
Group Statistics

Score

Variable	Group	N	Mean	SD	t value
Child Therapy	Yes	105	78.07	2.350	8.279
	No	95	80.57	1.866	

The mean value of Table 17 denoted that the parents whose IDD child was provided with early intervention therapy secured 78.07 mean value and the parents whose IDD child did not get any early intervention therapy secured mean value of 80.57. Based on the mean value, 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. The obtained t value is 8.279. The t value is greater than the critical value. Therefore, the null hypothesis is rejected and it is concluded that there is a significant mean difference in needs of parents on the basis of early intervention therapy provided to their IDD children.

H_{018}. There will be no significant mean difference in needs of parents on the basis of the availability of training about management of their child

Table 18. t-Test
Group Statistics

Score

Variable	Group	N	Mean	SD	t value
Parents' training	Yes	13	77.69	1.888	2.387
	No	187	79.36	2.473	

The mean value of Table 18 denoted that the parents who did a training course about management of their IDD child secured 77.69 mean value and the parents who did not get any training about management of their IDD child secured mean value of 79.36. Based on the mean value, 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. The obtained t value is 2.387. The t value is greater than the critical value. Therefore, the null hypothesis is rejected and it is concluded that there is a significant mean difference in needs of parents on the basis of the availability of training about management of their child.

4.2.2. Assessing Relationships among Knowledge, Problems and Needs of Parents

The researcher applied Pearson Correlation Coefficient to assess the relationship among parent’s knowledge, problems and needs. Results are given below:

Table 19. Correlations between Knowledge and Problems

		K Score	P Score
K Score	Pearson Correlation	1	-0.206**
	Sig (2-tailed)		0.003
	N	200	200
P Score	Pearson Correlation	-0.206**	1
	Sig (2-tailed)	0.003	
	N	200	200

** Correlation is significant at the 0.01 level (2-tailed).

A Pearson Correlation Coefficient was computed in Table 19 to assess the relationship between the two variables, i.e., knowledge of parents and problems faced by parents. There was a significant negative correlation between the two variables, r= -.206, n=200; and the relationship was significant (p= .003).

Table 20. Correlations between Problems and Needs

		P Score	N Score
P Score	Pearson Correlation	1	0.077
	Sig (2-tailed)		0.279
	N	200	200
N Score	Pearson Correlation	0.077	1
	Sig (2-tailed)	0.279	
	N	200	200

A Pearson Correlation Coefficient was computed in Table 20 to assess the relationship between the two variables, i.e., problems of parents and needs of parents. There was a positive correlation between the two variables, r=.077, n= 200; however the relationship was not significant (p= .279).

Table 21. Correlations between Knowledge and Needs

		N Score	K Score
N Score	Pearson Correlation	1	-0.395**
	Sig (2-tailed)		0.000
	N	200	200
K Score	Pearson Correlation	-0.395**	1
	Sig (2-tailed)	0.000	
	N	200	200

** Correlation is significant at the 0.01 level (2-tailed).

A Pearson Correlation Coefficient was computed in Table 21 to assess the relationship between the two variables, i.e., knowledge of parents and needs of parents. There was a significant negative correlation between the two variables, r= -.395, n=200; and the relationship was significant (p= .000).

Table 22: Summary of the Inferences

No of Hypotheses	Hypotheses	Inference
H_{01}	There will be no significant mean difference in knowledge of parents about IDD on the basis of their gender	Accepted
H_{02}	There will be no significant mean difference in knowledge of parents about IDD on the basis of their age	Rejected
H_{03}	There will be no significant mean difference in knowledge of parents about IDD on the basis of their education	Rejected
H_{04}	There will be no significant mean difference in knowledge of parents about IDD on the basis of their occupation	Rejected
H_{05}	There will be no significant mean difference in knowledge of parents about IDD on the basis of their residential background	Rejected
H_{06}	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_{07}	There will be no significant mean difference in problems faced by the parents on the basis of their gender.	Accepted

No of Hypotheses	Hypotheses	Inference
H_{08}	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_{09}	There will be no significant mean difference in problems faced by the parents on the basis of their income	Rejected
H_{010}	There will be no significant mean difference in problems faced by the parents on the basis of their residential background	Accepted
H_{011}	There will be no significant mean difference in problems faced by the parents on the basis of the type of their family.	Rejected
H_{012}	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
H_{013}	There will be no significant mean difference in problems faced by the parents on the basis of the gender of their disabled child	Accepted
H_{014}	There will be no significant mean difference in needs of parents on the basis of the level of the disability of their children	Accepted
H_{015}	There will be no significant mean difference in needs of parents on the basis of their income	Rejected
H_{016}	There will be no significant mean difference in needs of parents on the basis of their residential background	Rejected
H_{017}	There will be no significant mean difference in needs of parents on the basis of early intervention therapy provided to their IDD children	Rejected
H_{018}	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

4.3. Analysis of Qualitative Data

4.3.1. Case Study Reports

The researcher conducted individual case studies of parents having children with IDD and explored the experiences of those parents to determine the problems and needs associated with raising a child with IDD. Twenty (20) parents were purposively selected from parents whose IDD children attended special schools or regular schools. Parents who consented to be interviewed with voice recorder were included in the interview process. Parents of IDD children were interviewed using semi-structured interview to gather data on their experiences. During the interview, participants were asked about their demographic details, their experiences as parents of an IDD child, the obstacles they faced, as well as necessary support and needs.

All the audio recordings were then transcribed after the completion of interview through MS Word Processing programme. The recordings were translated into English before transcribing them. The researcher also checked those transcribed data to make sure all interview information were accurately captured.

Case Study 1

Mrs. Shrirupa is a school teacher aged 40 years old and a mother of a 15 years old daughter. Her daughter has a mild intellectual and developmental disability. She has mild Autism. She had also Epilepsy during her childhood but the effect of that Epilepsy is weaken now. They live as a nuclear family in an urban area in Kolkata. Their daughter remains very weak almost all the time. The Parent is more concerned about the her physical health than intellectual problems because they had to spend a long time in the hospitals for her treatment. She loves and cares for her child very much and she believes that it was by proper treatment and parental support her child will grow as per her potential. But she has a fear about the safety of her child. She doesn't trust anyone regarding the safety of her child as there are a lot of abuse cases happening around the world so she is very much worried about that.

Case Study 2

Madhuboni (Age: 44) is a housewife and a mother of her 13 year old daughter named Sreeja. Sreeja has moderate Autism. Madhuboni live in a nuclear family in a area near Kolkata. After almost three years of birth of Sreeja, Madhuboni realized that there is a problem in her child. But she didn't know about the exact condition. She was admitted to a regular school where her daughter was very obedient and active in her initial school days. But day by day she showed some lackings in communication skill, slowed in academics. Madhuboni's husband is a school teacher and after consultation with other colleagues her husband and she took their child to a doctor for exact diagnosis and the report confirmed about autism. That time both Madhuboni and her husband were shattered as they had no idea about the consequences of the disability. . After 5 years her child started showing very violent behavior. So the child underwent medication. When her daughter became sexually matured, she had to face sexual harassment by a relative of them when they went to a house gathering. After that incident, the child started showing fearsome behaviour towards boys. During that time the Madhuboni suffered a lot because the child was not ready to get accepted or adapted to that situation. On the other hand her husband is supportive of the child but he didn't know how to deal with his differently abled child. So finally they admitted her to a reputed special school in Kolkata for therapy. Now Sreeja is showing improvements after some therapies and also improvements are shown in academics with the help of her special teachers. But still Madhuboni is anxious about her child's safety as she had to face an abuse. So she doesn't leave her child alone anytime.

Case Study 3

Sumana is a 38 year old house wife and a mother of a 11 years old boy named Akash . Akash has Mild level of Intellectual Disability. They live in a nuclear family in South 24 Pgs district. Akash's disability was identified before he reached two year old. Although Sumana was initially depressed because of the child's disability, later she tried to understand the abilities and potentials of her child and worked to uplift him at their best. Now Akash tries to do his daily chores by himself. As the child shows more interest in dancing,Sumana is giving priority to develop his skill. Akash got prizes in many dance programmes. She said that she didn't get much support from her in laws but her own parent is so much supportive. Her husband also supports her. Akash went to normal school for one year but didn't continue because of the lack of support from the teachers and the institution there. Sumana suffered a lot of stress because Akash didn't get the appropriate care and support that he really needed from that regular school. So she admitted her child to a special school in Kolkata. Things began to change after Akash got admission in special school. She said that she received all the support from that institution. She also said that she was worried about who will take care of her child after her death. Akash sometimes becomes violent and tortures her mother, but she stays calm that leads the child also to calm himself. She wants to give a message to the society from her experience that along with the children, parents especially mothers should receive care and support. Also she says that such students should be sent to special schools only as regular schools have not proper resources for the child. She said that it is the decision of the Almighty to have this child so she will take care of him without any regrets till her death.

Case Study 4

Ankita is a housewife. She is 34 years old. Her baby girl (Trisha) could talk earlier. For two years she was completely normal, she could speak. She had no walking delay or speech delay then. After two years Ankita suddenly noticed that Trisha started living completely alone. She slowed down talking. She didn't want to play at all. She stopped playing with toys as before. First Ankita and her husband lived in Mumbai. They went to Dr Samir Dalwai. They then came to know from him that Trisha has Autism and ADHD. She did not want to sit in one place. Ankita and her husband then admitted her to a normal play group so that she can play and talk to other children of her age. She used to go to classes regularly but nothing positive was seen in her behaviours. Since then, they started her therapy. But after knowing that she has Autism, Ankita was little depressed as her child and she used to stay alone at home all day. Her husband was on tour all day. So she could not handle all this and was getting depressed. They also went to NIMHANS. They then told Ankita to stay with her parents, friends and family so that she would be better. Because if she is good, the child will be good too. Then she moved to Kolkata and started living with her parents. Husband lived there in Mumbai as he has his workloads. After coming here, Ankita sent her child to a special school. She also kept a special educator at home. She learned about teaching with special materials from the Special Educator there. Before she had no idea about this kind of disability. Now she knows a little bit. When that special educator was teaching, she said, she used to sit with him sometimes. She learned something from him, for example, her child used to be very afraid of cutting her nails, cutting her hair, then she was afraid of loud noises. Earlier, she had to be told through a story or by showing a picture or video that "today I will cut my nails, this is how I cut my nails." If there is a sound of "Dhaak", first Ankita tells her the story that such a sound is made during puja. She (Trisha) can understand these then. Ankita has never received much support from her in-laws, but her parents have been very supportive of her and her child. She said, "if you do the survey, you will see that in 99% of the cases, the father-in-law did not get any support!" Her husband is very supportive though. He treated her very well..

Trisha loves to go to school. But she has not many friends still now. However, she is not as upset as before. Therapy is still ongoing. Speech development is not yet observed as such. Trisha can speak only one or two words and always wants to be around mother. She can't say everything properly, so if Ankita doesn't understand something, her child gets very angry and cries. Because she hopes that her mother will understand everything, Trisha said. She doesn't take her everywhere, she takes her where everyone will understand her. She always takes care of such things so that no one will question her wrongly when she goes there. If someone asks, "Your child is not normal?" Why do you look like that?" Even if her child can't say it, she understands it. She can't go everywhere by bus or train, because Trisha grabs someone's hair and harms them.. That's why the hire Ola or Uber and goes everywhere. This is a disadvantage. Money is also very expensive. But there is nothing to do.
Other expenses are deductible while taking care of the child. Ankita would like to say to the Government that not only the parents below the poverty line will have financial needs, but they also need financial support.

Case Study 5

Mr. Abdul is a 46 year old government employee and a father of 14 year old son named Azaad. Azaad has moderate level of Autism. They live in a nuclear family in Garia, Kolkata. Azaad had normal growth and development like other children until the age of three. He had Epilepsy and had brain injury due to this. Later his brain development became very slow. Medications for epilepsy are still going on, Abdul said. Doctors confirmed that the child had a moderate level of intellectual disability. According to the doctors the brain damage was the cause of intellectual disability in children. Abdul and his wife Fatima are government employees in Baruipur. Abdul said that his biggest stress is due to lack of cooperation and anger of the child in his daily chores activities. Abdul lives in a nuclear family so it's very difficult for him to seek someone's support when his child is showing disturbances. That gave him a lot of problems in his professional work also. All his relatives were away from them so he couldn't obtain their proper support also. Abdul relieves his stress by spending time with his child, taking him for outings, playing with him etc. This Child came across many changes by the training and special care from the special school. Abdul didn't feel like he had to spend extra money for his child's disability. He said that many awareness and training from governmental and non-governmental sectors were very useful for such children but they should focus on this more and more so that these schemes and programs reach the needed parent on time.

Case Study 6

Mrs. Aditi shared her bitter life experiences because of the her child's condition. Her child has moderate Autism and she is non verbal. Mrs. Aditi was always blamed by in-laws and relatives. She is a working women in private company. And her in laws blamed that her child has these problems as she went for work during pregnancy. They didn’t like her going to work. Aditi even thought of leaving her family along with her child when she was being ignored from relatives and society. But she didn’t because despite all these problems she is getting good support from her husband. She is not fully aware of the child's disabilities. And she admits that it is mandatory for parents of children with such disabilities to participate in various awareness programmes and ensure the early intervention methods for the development of children.

Case Study 7

Atasi is a 28 years old housewife and a mother of a 9 years old son named Ankit. This child has Mild level of intellectual disability. She lives in a nuclear family in Kolkata with her husband and Ankit. Atasi is still reluctant to believe that Ankit has intellectual disability. When Ankit was four years old he was diagnosed with Autism by a doctor. So Atasi and her husband consulted their child in homeopathy, allopathy, Ayurveda etc. for treatment. In this condition of the child the young mother Atasi suffered high levels of stress and she cannot even lead a good family life. Ankit went to regular school for a few months but later he didn’t go regularly. He is not able to do anything himself, so he always seeks mother’s support for eating, dressing, bathing, and other daily living activities. This gives her lots of stress and anxiety.

Case Study 8

Rajlakshmi is a 42 years old mother and a school teacher. She has two children in which youngest son Devangshu (16 years old) is having Moderate level IDD. Rajlakshmi had to face lots of problems from her relatives and society because of her child’s condition. Devanshu joined a special school when he was twelve years old. When he was seven years old, he joined the regular school but found it difficult to continue there and after that his studies stopped. Rajlakshmi said that she has no idea how to teach him and to train him for his daily activities. It was in an awareness programme conducted by a local NGO and one of her colleague in school where she came to know about such special schools for IDD children. Devangshu developed lots of positive behavioural changes after going to special school. Rajlakshmi has a 21 years old daughter. She was stressed the most due to Devangshu’s disability when her daughter’s marriage proposals were coming. When the marriage proposals were coming, the groom’s side family had biggest doubt that her brother’s disability was hereditary and may this disability be passed on to the next generation also.

Case Study 9

Veena is 39 years old and a mother of two children. Among them, Abhash (Son) is a moderate level of Intellectually Disabled child. Her son is now 14 years old. They live as a nuclear family near Kolkata. The doctor informed that the child had Intellectual and other physical disabilities. But Veena couldn't accept the child’s condition. She used to stay with Abhash while he goes to special school. She feels relieved as she can share her experiences with other mothers of disabled children. The biggest stress of Veena is that her son behaves very aggressively when he is in a public place. Varsha’s elder child is a girl and her husband is also very supportive to her but other relatives are not interested to pay attention to her child's condition. Husband’s family blames her for the child's disability. This issue makes her mentally depressed.

Case Study 10

Krishna Majumder, aged 39, is a widowed women. She passed Higher Secondary. Her child has mild Autism. His name is Krish. He is 12 years old. He was seen by a doctor when he was three years old. She used to live in Odisha with her son and husband. Then her family doctor said that Krish is growing and still not able to speak properly, so asked to observe for another year. Then when he was four years old they moved to Kolkata for his treatment. There he was diagnosed with autism. After three years from then her husband died and since hen she has been bringing up her child alone. This gives her lots of stress, anxiety and pain in life. No body showed a supportive hand to her. She then started to give her house on rent to girls and bears the expenses of her child’s treatment from that. So financial problem is a big problem she said.

Case Study 11

Aruna is a 32 years old private employee. She has a child named Vihaan who has Down Syndrome. Vihaan is 9 years old. He can’t fulfil his basic needs without the help of others. Aruna’s husband and her parents are very supportive related to child matters. But nowadays, Aruna and her husband are facing problems because their child starts showing hyper activities when he stays in public. It makes it difficult for them to travel with him in public transport or to attend public functions. Her relatives and friends are also very supportive to them. When the family wants to go outside for any urgent work, their relatives and friends take care of the child. Aruna’s view is against the society who shows sympathetic attitudes towards the disabled children. As a mother she does not agree with this sympathy instead these children needs empathetic attitude and positive and practical social support.

Case Study 12

Mrs. Mandira (35 years old) is a high school teacher and a mother of a 12 year old son named Pratham. Pratham has Mild Intellectual disability. They live as a Joint family in Kolkata. Now she is on leave for the last few months when her son started showing violent behaviour. Till fourth standard, her son studied very well in a reputed English Medium school in Kolkata. After that he started showing symptoms of disability, and gradually her child started losing the ability to understand and to remember. After realizing that her son has a mild level of IDD, she went for better treatment for her son. Same time her son showed hehisr interest in music and dance. He has also been showing very violent behaviour for the past few months but when she applied music therapy for the child; gradually Pratham started changing and reduced his violent nature. Mandira said that music therapy is a good treatment for such type of disabled children. Her child was showing good attitude only with parents and his school teachers while he showed violent behaviour with others. Her husband and family members are very supportive of her. She suggested that society needs to change their mentality towards such children. She shared two shortcomings also, one is after the death of them, no residential home available in Kolkata for such children. The second is that many special training schools follow same conventional training methods where differently abled children are studying, and should need to adapt and apply new treatment and training methods in these institutions as in other states of India and in foreign countries.

Case Study 13

Reema (36 years) is a housewife and mother of a 15 year old son named Roni. This child has moderate level intellectual disability. They live in a nuclear family in a rural area near Kolkata. During the case study the mother recalled her stressful days when her child's disability was identified for the first time. Reema gave birth to Roni by caesarean; but Roni didn't cry after the delivery. Reema was skeptical, even though the baby did not responding to other sounds and milk feed. But she realized that the development of the child was very slow as compared to normal children. At that time, Reema was depressed completely and she was mentally and physically down when she felt helpless about her child's condition. The child was not able to walk until he was three years old. After consulting with the doctor, she realized that there was no cure for this disease.

Case Study 14

Mukti is a 38 years old working woman and a mother of an 12 years old daughter named Ankita. This child has Mild level of Aurism. She lives in a nuclear family in Kolkata with her husband and Ankita. Mukti shares her concerns regarding her daughter's hormonal changes, sexual urges and period. She was anxious to ask about how to make her daughter understand about menstruation and how to handle the situation when her daughter will experience first period. She was very anxious her daughter's safety as she is developing fully and there are so many instances like physical abuses. She wants help from Govt for these things.

Case Study 15

Asha is a 40 year old housewife who lives in a rural area of Kolkata along with her three children and her husband. Asha's second son has down syndrome. Other two children are absolutely fine. Asha didn't have any idea about thus disability as she is a mere housewife who completed her 10t only. Her husband is a daily wage earner. So they have financial problems too. When the researcher asked them abut the schooling of their child , they told that they can't afford much for his education and they thought this is a waste of money. Her other two children study in a govt primary school. But they didn't send their disabled child to school because they leave it to the Almighty.

Case Study 16

Sourav Roy is a father of a 12 year son named Ankush who has Mild Autism. Sourav is an IT employee. He can't take care of his son all the time so he kept a special educator at home for Ankush. Ankush's mother Rina spends all the time with her son. She left her job for taking care of Ankush. Sourav acknowledges his wife's sacrifice but Rina showed sadness and frustration to the researcher as she left the job. Rina also misses her parents sometimes as she can't handle Ankush always. Sourav and Rina sometimes have quarrel regarding their child's condition and this hampers their peace of mind too, they admitted. But they try to take best possible care for their child.

Case Study 17

Devangana is a School Teacher (35) and a mother of 13 year old son, Priyo. Priyo was identified with Down Syndrome. Devangana got divorced when her child was three years old and now she lives alone with her son in Kolkata. She is suffering from high blood pressure and is worried about her child's future. Her parents accepted their grandson and sometimes visit them in Kolkata. But being a divorcee, Devangana has to face some problems while taking her son to social gatherings. So she avoids those gatherings. But she made some good friends in special school where other mothers come with their disabled child.

Case Study 18

Mrs. Rajani is a 39 year old housewife and a mother of 8 year old son Barun. Barun has moderate Autism. She sends her son to a special school. Sometimes her son becomes violent and harms himself. This gives her lots of stress. She requested NGOs, Govt for some kind of short trainings without free of cost for managing these children because financial issue is always there while taking care of these children. She wants to receive more information on this disability and more awareness programmes, care and support for parents.

Case Study 19

Godhuli Roy started crying while giving interview. She lost her husband when she gave birth to her son. After two years her son was diagnosed with Moderate Autism. Her son is very inattentive, hyper active and aggressive at this 13 years of age. She is so worried about her son's hormonal changes. Her son can't change shirts, pants properly, combo hair properly and can't eat properly. He is admitted to a special school but till now he is not showing any improvement there. She is facing financial issues. Her parents are very supportive though but she misses her husband and regrets that if her husband were alive, managing her son could be easier.

Case Study 20

Reena is a private employee (28 years old) and a mother of a 6 years old son. Reena and her husband had a love marriage. But after their son's birth her husband is showing reluctance and indifference to their relationships. They had quarrel most of the times regarding their son's condition. Though she is hopeful that her son will improve. Her in laws are also not supportive. As she earns money by herself so she handles all the expenses. Her husband is not cooperating with her that much and that give her pain. But she urges to Govt to arrange some kind of special homes for children with disability so that after their death their children can survive.

Six major themes from the analysis and interpretation of the data, were derived:

1. Emotional reactions
2. Social reactions
3. Knowledge about the condition
4. Cause of the condition

5. caregiving challenges
6. Needs to raise the IDD child.

The table below outlines the key themes and sub themes from the case studies.

Table 23: Themes and Sub-themes Emerged from Case Studies

Themes	Sub-themes
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 Challanges	Management of the child
	Safety Issues
	Employment and financial issue
Needs to raise IDD child	Support Services and financial help
	Govt benefits

1. **Emotional Reactions:** Parents of IDD children stated their feelings of sadness, concerns for the future, and also stress and anxiety about looking after their IDD child.

1.1. Sadness: Every parent acknowledged that finding out about their child's conditions caused them to feel depressed. Statements from certain parents serve as examples of this:

> “On that day when I came to know that our child has Down Syndrome I cried a lot. I have two kids now. And I was very delighted to have a baby girl as my first child since that is what I wanted, but when the doctor told me about my child’s condition, my husband and I was shattered I sobbed a lot.”

1.2. Worry About Future: Most of the parents in this study expressed their confusion and concern about the current and future condition of their IDD child. They were especially worried that their child was not reaching milestones and would not be able to be independent in the future. Two parents worried about how their child is growing and what will happen in the future. The following quotes from two parents illustrate this:

> “I am so much concerned about his future because even though he is almost ten years old, there are many things he cannot perform on his own. He is not been able of walking properly or communicating with other things. When we will not be there what will be his condition that worried me a lot.”

> “I am very worried about his future because as of now he can’t talk, do anything himself and has to rely on us completely. So one day when I die, he will be alone, what will he do then! Who will take care of him?”

1.3. Stress: Parents also talked about how difficult it is to care for a child with IDD. One of the parents made the following statement:

> “Every parent become stressed in raising a children as parenting is not that easy enough! But the stress associated with raising a child with Autism or Down syndrome or any other disabilities like this is very deep. Your child is always running up and down and always shouting and you need to control her, which is very stressful. Thinking of all the sacrifices you have to make for her development and how to get her through the daily activities, getting the other disciplines to understand the situation, financing her education to special schools, which is more expensive than regular school. It is truly a lot of trouble.”

2. **Social Reactions:** All parents, during the interview, expressed that having an IDD child was like a transition into a new and often unwelcome identity in society even to some of the family members too. Parents expressed their awareness of societal attitudes which made them feel stigmatized and isolated. This is illustrated in the following narratives by one of the parents:

2.1. Stigma: Some parents expressed that though the world is growing scientifically but there are some stigmas related to disabilities still exists:

> “Its a very difficult journey of having a child with special needs. In this society, it is a taboo to have and people often say that you have a child with intellectual disability because of something bad you have done. And if it is a mother then the blame is always on you!”

2.2. Isolation: Parents also admitted feelings of loneliness and being left out of the wider community due to their IDD children. A mother explained how things are for her:

> “l cannot take my daughter out to any social program or gathering all the time. This is not that I want her not to go but this is because l do not like the way other people would look at her. Instead of asking what is wrong with her they stare at her and l feel very bad so I stay with her in the house and attend those functions where she is accepted.”

3. **Knowledge about the Condition:** This theme described the different ways in which mothers learned about their children's conditions. Mothers indicated that they knew about their children's condition from three sources, including their personal information from observing the child's physical characteristics, medical or psychological consultation, and teacher information.

3.1. Personal Knowledge: 20% parents, during their interview, expressed the doubts about their child’s development. It was regarding the physical characteristics of these children as well as developmental delay. One parent said,

> “It was a few months after giving birth that I realized there was a problem with my baby. . . As my husband is a doctor so I have some knowledge about these conditions, I know their characteristics and speed of development. My child had Down syndrome features like a round face, slanted eyes, I knew something was wrong. Still not talking but he was crying a lot, he just looked and was quiet and I didn't know if he was hungry or wet. I knew something was wrong.”

3.2. Medical Diagnosis: 60% parents in this study reported uncertainty about their child's developmental delay. To understand what happened, the parents reported seeking medical attention:

> “Because of his developmental delay, I took him to the child specialist and the doctor told me that my son has PDDNOS and Autism which doesn’t make him grow normally.”

3.3. Teacher Information: 20% parents stated that they came to know about their child’s condition from teachers in regular schools. The children did not behave like other school children and did not behave properly. One parent told,

> “His teacher told my husband that when she teaches the child, he does not understand. When she asks my child a question, he just looks here and there. He doesn't say anything or doesn’t communicate.”

4. **Cause of the Condition:** Most parents relayed the explanation provided by doctors about the condition of their child and the cause of that. Well, most of the educated parents reported being aware of the medical condition of having an IDD child. But some parents being not that much educated and living in rural areas reported that having an IDD child depends on the will of God or luck. A statement in favour of medical condition is illustrated: “After My child was diagnosed with Down syndrome, I understand that may be it is because I got pregnant at the age of 41 which was definitely a late pregnancy.”

5. **Caregiving Challenges:** Parents reported their challenges and problems involved in raising an IDD child. These problems were explained below:

5.1. Management of the Child: The parents reported a greater problem regarding the management of the child. They need to assist the child in carrying out everyday tasks like brushing teeth, having food, using toilet, taking bath, and getting dressed. One parent stated:

> "I have to go through a lot of works during a normal day. In the morning when I wake up, I have to brush his teeth which became difficult for me. I have to bath him, dress him, feed him and literally do everything for him. I don't get any fair time for myself. The issue is that he cannot do anything for himself so I have to help him out all the time. I have to take him school and till the end I have to sit by his side so that he doesn't disturb or doesn't get hyper and hurt himself or others."

5.2. Safety Issues: All parents showed their anxiety regarding the safety issues of their child with IDD. One parent of a female IDD child reported:

> "My daughter is now 15 years old. And I have fear how I keep her safe always. I can't keep her all the time with me. Sometimes she has to get a therapy session to a teacher. And if he is a male teacher I have to take extra care of that. You know about female harassment right! Even in the family also I have to take extra care to keep her safe because if something bad happens she can't even speak about the problem!"

5.3. Employment and Financial Issue: All parents expressed how difficult it is to find and retain a job while supporting their IDD children, leading to financial difficulties. One mother of an IDD child described his experiences as follows:

> "Earlier I had many plans of working and having a great career, but because of my son was diagnosed with Moderate level of Autism, I had to admit the fact that I have to chose to be a caregiver all my life instead of a hectic work life. I cannot work like other women do. I made a decision to stop working as l could not work and also take care of my son at the same time."

One father of an IDD child reported about his financial condition :

> "I am currently working as a sales manager and my salary is not that much high. Because I have to do many therapy session for my child I have to cut all sorts of extra expenditure for the betterment of my son. I have to buy medicines, I have to give fees to the special schools which sometimes gives me stress to manage those monetary problems."

6. **Needs Associated with Raising IDD Child:** Almost all the parents reported greater needs in the field of support services, financial help and Govt benefits. Parents want child level support services and interventions. Parents do need information about state as well as central

government benefits, legislations and provisions of services in order to raise child with IDD. One illustration by a parent goes like,

> “I want to admit my son to a regular school but my worry is I don’t know about the facilities he will be provided there. Only admitting him to a regular school is not enough. I want to know what Govt is providing us to support his needs there. Even when I admit him in special schools I have to spend lot of money for bearing the expenditure which be comely costlier for mediocre family like us. So what are the Govt benefits, schemes to cope up with this financial crisis is a must know for all parents like us.”

CHAPTER - V

FINDINGS AND DISCUSSION

5.1. Findings

The present study assessed the knowledge, problems and needs of parents of Intellectually and Developmentally Disabled Children in West Bengal, India. The findings of the study are mentioned below.

5.1.1. 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 that 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 who 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.

5.1.2. 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.

5.1.3. 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.

5.1.4. 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.

5.2. Discussion Related to the knowledge, problems and needs of parents of Intellectually and Developmentally Disabled Children

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 with 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.

5.3. Implications

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.

5.4. Recommendations

This study looked at what parents of children with IDD know about that disability, what problems they have, and what help they need. It made some suggestions for how to better support these parents. It suggests that government, NGOs, schools, and community leaders should all work together to help parents of children with intellectual or developmental disabilities. This will help improve the quality of life for these families. Understanding the problems and needs of parents better can help the government make better policies and provide more support to the caregivers of children with disabilities.

5.3. Limitations

1. The study was limited to only 200 parents of IDD children. So generalisation cannot be made.
2. Self made standardised tools could be developed by the researcher.
3. The researcher could not take interviews of many fathers as fathers were not been able to give enough time to the researcher as they had to go to the jobs or were not available at the time of interview.

5.4. 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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CHAPTER – 6

RESEARCH SUMMARY AND CONCLUSION

6.1 Introduction

6.2 Review of Related Literatures

6.3. Knowledge Gap

6.4. Statement of the Problem

6.5. Objectives of the Study

6.6. Hypotheses

6.7. Research Methodology

6.8. Data Analysis and Interpretations

6.9. The Findings

6.10. Conclusion

6.1. 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," "feebleminded," 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).

6.2. Review of Related Literatures

The researcher conducted 101 literature reviews to formulate her current research. She did 61 reviews of the studies conducted in abroad and 39 literature reviews of the studies conducted in India.

6.3. 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.

6.4. 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.***

6.5. Objectives

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

6.6. Hypotheses

H_{01}. There will be no significant mean difference in knowledge of parents about IDD on the basis of their gender

H_{02}. There will be no significant mean difference in knowledge of parents about IDD on the basis of their age

H_{03}. There will be no significant mean difference in knowledge of parents about IDD on the basis of their education

H_{04}. There will be no significant mean difference in knowledge of parents about IDD on the basis of their occupation

H_{05}. There will be no significant mean difference in knowledge of parents about IDD on the basis of their residential background

H_{06}. There will be no significant mean difference in knowledge of parents on the basis of early intervention therapy provided to their IDD children

H_{07}. There will be no significant mean difference in problems faced by the parents on the basis of their gender.

H_{08}. 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_{09}. There will be no significant mean difference in problems faced by the parents on the basis of their income

H_{010}. There will be no significant mean difference in problems faced by the parents on the basis of their residential background

H_{011}. There will be no significant mean difference in problems faced by the parents on the basis of the type of their family

H_{012}. 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_{013}. There will be no significant mean difference in needs of parents on the basis of the gender of their differently abled child

H_{014}. There will be no significant mean difference in needs of parents on the basis of the level of disability of their children

H_{015}. There will be no significant mean difference in needs of parents on the basis of their income

H_{016}. There will be no significant mean difference in needs of parents on the basis of their residential background

H_{017}. There will be no significant mean difference in needs of parents on the basis of early intervention therapy provided to their IDD children

H_{018}. There will be no significant mean difference in needs of parents on the basis of the availability of training about management of their child

6.7. Research Methodology

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

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 snd 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.

6.8. Data Analysis and Interpretations

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_{01}	There will be no significant mean difference in knowledge of parents about IDD on the basis of their gender	Accepted
H_{02}	There will be no significant mean difference in knowledge of parents about IDD on the basis of their age	Rejected
H_{03}	There will be no significant mean difference in knowledge of parents about IDD on the basis of their education	Rejected
H_{04}	There will be no significant mean difference in knowledge of parents about IDD on the basis of their occupation.	Rejected
H_{05}	There will be no significant mean difference in knowledge of parents about IDD on the basis of their residential background.	Rejected
H_{06}	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_{07}	There will be no significant mean difference in problems faced by the parents on the basis of their gender.	Accepted
H_{08}	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_{09}	There will be no significant mean difference in problems faced by the parents on the basis of their income	Rejected

No of Hypotheses	Hypotheses	Inference
H_{010}	There will be no significant mean difference in problems faced by the parents on the basis of their residential background	Accepted
H_{011}	There will be no significant mean difference in problems faced by the parents on the basis of the type of their family.	Rejected
H_{012}	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
H_{013}	There will be no significant mean difference in problems faced by the parents on the basis of the gender of their disabled child.	Accepted
H_{014}	There will be no significant mean difference in needs of parents on the basis of the level of the disability of their children.	Accepted
H_{015}	There will be no significant mean difference in needs of parents on the basis of their income.	Rejected
H_{016}	There will be no significant mean difference in needs of parents on the basis of their residential background	Rejected
H_{017}	There will be no significant mean difference in needs of parents on the basis of early intervention therapy provided to their IDD children.	Rejected
H_{018}	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

Themes	Sub-themes
Emotional Reactions	Sadness
	Worry about future
	Stress
Social Reactions	Stigma
	Isolation
Knowledge about the Condition	Personal Knowledge
	Medical Diagnosis
	Teacher Information

Themes	Sub-themes
Cause of the Condition	Spiritual Beliefs
	Medical
Caregiving Challanges	Management of the child
	Safety Issues
	Employment and financial issue
Needs to raise IDD child	Support Services and financial help
	Govt benefits

6.9. Findings

- **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 that 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 who 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.

6.10. Conclusion

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.

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.

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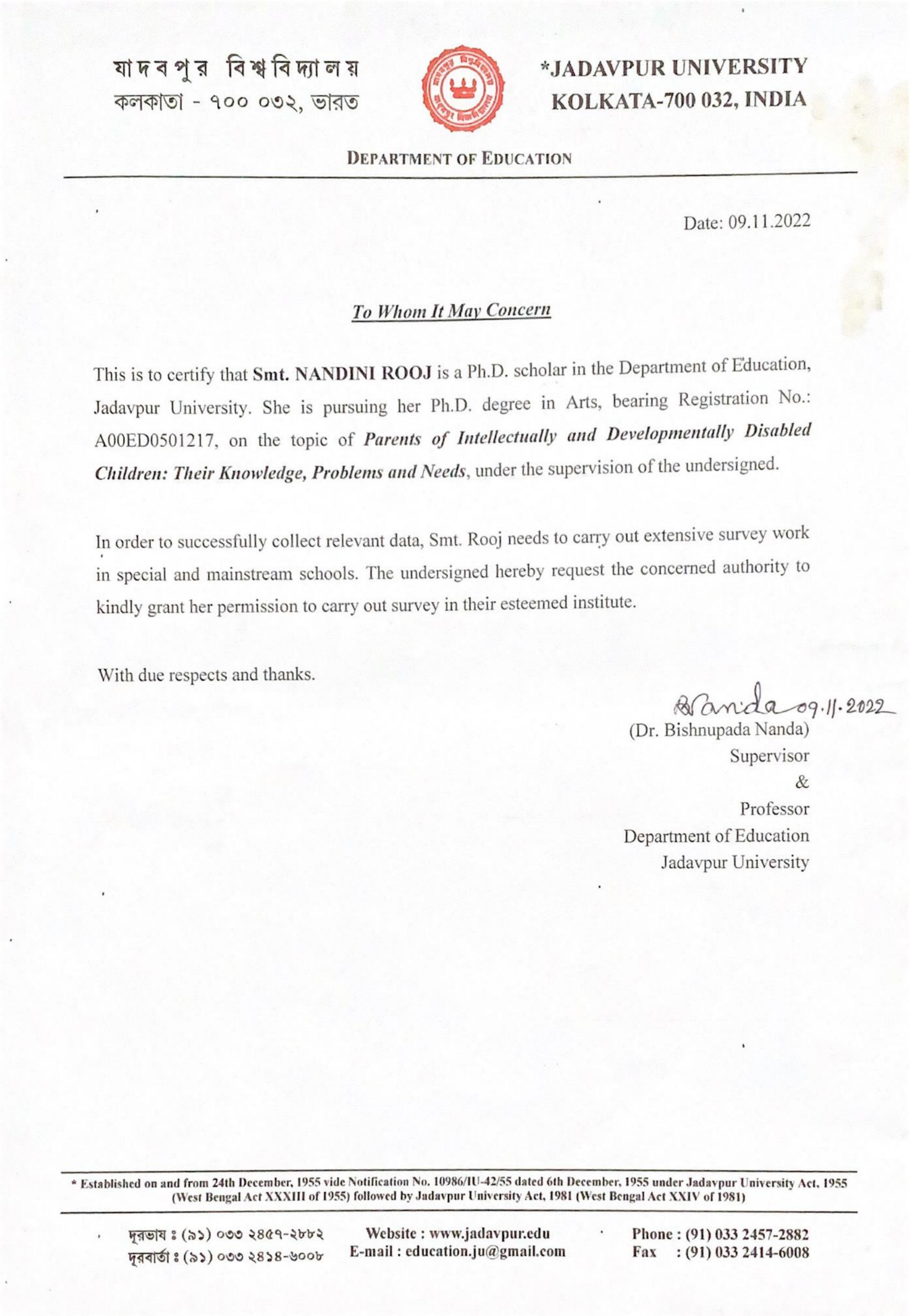
Appendix I

Permission Letter for Data Collection



যাদবপুর বিশ্ববিদ্যালয়
কলকাতা - ৭০০ ০৩২, ভারত

*JADAVPUR UNIVERSITY
KOLKATA-700 032, INDIA

DEPARTMENT OF EDUCATION

Date: 09.11.2022

To Whom It May Concern

This is to certify that **Smt. NANDINI ROOJ** is a Ph.D. scholar in the Department of Education, Jadavpur University. She is pursuing her Ph.D. degree in Arts, bearing Registration No.: A00ED0501217, on the topic of ***Parents of Intellectually and Developmentally Disabled Children: Their Knowledge, Problems and Needs***, under the supervision of the undersigned.

In order to successfully collect relevant data, Smt. Rooj needs to carry out extensive survey work in special and mainstream schools. The undersigned hereby request the concerned authority to kindly grant her permission to carry out survey in their esteemed institute.

With due respects and thanks.

Nanda 09.11.2022
(Dr. Bishnupada Nanda)
Supervisor
&
Professor
Department of Education
Jadavpur University

* Established on and from 24th December, 1955 vide Notification No. 10986/IU-42/55 dated 6th December, 1955 under Jadavpur University Act, 1955 (West Bengal Act XXXIII of 1955) followed by Jadavpur University Act, 1981 (West Bengal Act XXIV of 1981)

দূরভাষ ঃ (৯১) ০৩৩ ২৪৫৭-২৮৮২
দূরবার্তা ঃ (৯১) ০৩৩ ২৪১৪-৬০০৮

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Appendix II

Questionnaire to Measure Knowledge of Parents about Intellectual and Developmental Disabilities

SL. NO.	STATEMENT	RESPONSE	
		YES	NO
I General Information about Intellectual and Developmental disability			
1	Intellectual and Developmental Disability is found at any age. যে কোনো বয়সেই বৌদ্ধিক ও বিকাশগত অক্ষমতা দেখা দিতে পারে।		
2	Intellectual and Developmental Disability is an infectious disease. বৌদ্ধিক ও বিকাশগত অক্ষমতা একটি সংক্রামক রোগ।		
3	Intellectual and Developmental Disability can be cured. বৌদ্ধিক ও বিকাশগত অক্ষমতা নিরাময় করা যেতে পারে।		
4	Children with Intellectual and Developmental Disability do not follow instruction. বৌদ্ধিক ও বিকাশগত অক্ষম শিশুরা নির্দেশ অনুসরণ করে না।		
5	Intellectual and Developmental Disability is due to black magic. কালো জাদুর কারণে বৌদ্ধিক ও বিকাশগত অক্ষমতা হয়।		
6	Medicines can cure Intellectual and Developmental Disability. ওষুধ বৌদ্ধিক ও বিকাশগত অক্ষমতা নিরাময় করতে পারে।		
7	Traditional healers can cure Intellectual and Developmental Disability. ঐতিহ্যগত নিরাময়কারীরা বৌদ্ধিক ও বিকাশগত অক্ষমতা নিরাময় করতে পারে।		
8	Children born during solar/lunar eclipse become Intellectually and Developmentally Disabled . সূর্য/চন্দ্রগ্রহণের সময় জন্ম নেওয়া শিশুরা বৌদ্ধিক ও বিকাশগত অক্ষম হয়ে পড়ে।		
9	Children with Intellectual and Developmental Disability cannot be taught like normal children. বৌদ্ধিক ও বিকাশগত অক্ষম শিশুদের সাধারণ শিশুদের মতো শেখানো যায় না।		
10	Children are born with Intellectual and Developmental Disability due to their sinful activity in previous incarnation. পূর্বে তাদের পাপ কর্মের কারণে শিশুরা বৌদ্ধিক ও বিকাশগত অক্ষম হয়ে জন্মায়।		
11	Giving a birth to a child with Intellectual and Developmental Disability is responsible due to fate of mother. বৌদ্ধিক ও বিকাশগত অক্ষম সন্তানের জন্ম দেওয়ার জন্য মায়ের ভাগ্য দায়ী।		

12	Intellectual and Developmental Disability are always hereditary. বৌদ্ধিক ও বিকাশগত অক্ষম সবসময় বংশগত।		
II Causes of Intellectual and Developmental Disability			
13	Malnutrition of a pregnant mother leads to Intellectual and Developmental Disability of child. গর্ভবতী মায়ের অপুষ্টি শিশুর বৌদ্ধিক ও বিকাশগত অক্ষমতার দিকে নিয়ে যায়।		
14	Consuming drugs/alcohol during pregnancy is harmful for the fetus & leads to birth of child with Intellectual and Developmental Disability. গর্ভাবস্থায় মাদক/অ্যালকোহল সেবন করা ভ্রূণের জন্য ক্ষতিকর এবং বৌদ্ধিক ও বিকাশগত অক্ষম শিশুর জন্ম দিতে পারে।		
15	Emotional/ physical trauma of mother may lead to Intellectual and Developmental Disability in child. মায়ের মানসিক/শারীরিক আঘাত শিশুর বৌদ্ধিক ও বিকাশগত অক্ষমতার কারণ হতে পারে।		
16	During pregnancy exposure of x-ray to mothers' fetus may lead to Intellectual and Developmental Disability. গর্ভাবস্থায় মায়েদের ভ্রূণের এক্স-রে করলে বৌদ্ধিক ও বিকাশগত অক্ষমতা হতে পারে।		
17	Pregnancy at an early age (below 18 years) leads to Intellectual and Developmental Disabilities. অল্প বয়সে গর্ভধারণ (18 বছরের নিচে) বৌদ্ধিক ও বিকাশগত অক্ষমতার দিকে নিয়ে যায়।		
18	Height of the mother is responsible for the child with Intellectual and Developmental Disability. বৌদ্ধিক ও বিকাশগত অক্ষম শিশুর জন্য মায়ের উচ্চতা দায়ী।		
19	Delayed birth cry also leads to Intellectual and Developmental Disability. জন্মের পর দেরিতে কান্নাও বৌদ্ধিক ও বিকাশগত অক্ষমতার দিকে নিয়ে যায়।		
20	Low birth weight leads to Intellectual and Developmental Disability. কম জন্মের ওজন বৌদ্ধিক ও বিকাশগত অক্ষমতার দিকে পরিচালিত করে।		
21	Immunization/vaccination leads to Intellectual and Developmental Disability. ইমিউনাইজেশন/টিকাদান বৌদ্ধিক ও বিকাশগত অক্ষমতার দিকে নিয়ে যায়।		
III Management of Intellectual and Developmental Disability			
22	Special teaching materials are required for teaching children with Intellectual and Developmental Disability. বৌদ্ধিক ও বিকাশগত অক্ষম শিশুদের শেখানোর জন্য বিশেষ শিক্ষা উপকরণ প্রয়োজন।		

23	Special teaching methodology is required for teaching children with Intellectual and Developmental Disability. বৌদ্ধিক ও বিকাশগত অক্ষম শিশুদের শেখানোর জন্য বিশেষ শিক্ষা পদ্ধতি প্রয়োজন.		
24	Special infrastructure is required for teaching children Intellectual and Developmental Disability. বৌদ্ধিক ও বিকাশগত অক্ষম শিশুদের শেখানোর জন্য বিশেষ অবকাঠামো প্রয়োজন।		
25	Medication is required to minimize the medical complications of children with Intellectual and Developmental Disability. বৌদ্ধিক ও বিকাশগত অক্ষম শিশুদের চিকিৎসা সংক্রান্ত জটিলতা কমানোর জন্য ওষুধের প্রয়োজন।		

Appendix III

Questionnaire: An Inventory on Problems of Parents Having Intellectual and Developmental Disabilities

General Information			
1	Name of the child (শিশুর নাম)		
2	Gender (লিঙ্গ)	Son (পুত্র) / Daughter (কন্যা) / Others (অন্য)	
3	Age of Child (শিশুর বয়স)		
4	Level of Disability (অক্ষমতার মাত্রা)		
5	Relationship of the respondent with child (শিশুর সঙ্গে উত্তরদাতার সম্পর্ক)	Mother (মাতা)	Father (পিতা)
6	Parent’s education (পিতামাতার শিক্ষাগত যোগ্যতা)		
7	Parent’s occupation (পিতামাতার পেশা)		
8	No. of siblings of IDD Child (IDD শিশুর ভাইবোনের সংখ্যা)		
9	Birth Order of IDD Child (IDD শিশুর জন্মের ক্রম)		
I	**Family Problems**		
Sl No.	**Problems Area**	**Yes (হ্যাঁ)**	**No (না)**
1	Do you blame each other knowing about child's condition? আপনি কি সন্তানের অবস্থা সম্পর্কে জানার পর একে অপরকে দোষারোপ করেন?		
2	Do you quarrel with spouse for bearing child's extra responsibility? আপনি কি সন্তানের অতিরিক্ত দায়িত্ব পালনের জন্য আপনার স্বামী/স্ত্রীর সাথে ঝগড়া করেন?		
3	Do in-laws find faults with you for the birth of IDD child? IDD শিশু জন্মের জন্য শ্বশুরবাড়ির লোকেরা কি আপনার দোষ খোঁজে?		
4	Spouse never accept my IDD child আমার স্বামী/স্ত্রী কখনই বৌদ্ধিক এবং বিকাশগতভাবে অক্ষম শিশুকে মেনে নিতে পারেননি		

5	Taking my child on vacation spoils the pleasure of the whole family. আমার ছেলে / মেয়েকে ছুটিতে নিয়ে গেলে পুরো পরিবারের আনন্দকে নষ্ট করে দেয়		
6	I have no privacy to share my feelings with my spouse জীবনসঙ্গীর সাথে আমার অনুভূতি শেয়ার করার কোন গোপনীয়তা নেই		
7	Caring for our IDD child limits the welfare of other siblings আমাদের বৌদ্ধিক এবং বিকাশগতভাবে অক্ষম শিশুর যত্ন নিতে গিয়ে অন্যান্য ভাইবোনদের কল্যাণের ক্ষেত্রে বাধা সৃষ্টি হয়।		
8	Our other siblings never accept our IDD child and tease him/her. আমাদের বৌদ্ধিক এবং বিকাশগতভাবে অক্ষম শিশুর ভাইবোনরা কখনই তাকে মেনে নিতে পারে না এবং তাকে জ্বালাতন করে		
9	Have you lost support from your spouse আপনি কি জীবনসঙ্গীর কাছ থেকে সহযোগিতা হারিয়েছেন?		
10	My spouse is irresponsible, unemployed and alcoholic spouse আমার স্বামী/স্ত্রী দায়িত্বজ্ঞানহীন বেকার ও মদ্যপ		
II	**Psychological Problems**		
1	When I noticed my child’s condition, I became shocked. (আমার শিশুটির অবস্থা দেখে আমি হতবাক হয়ে যাই)		
2	I worry about future of my IDD child. আমি আমার IDD বিশিষ্ট শিশুর ভবিষ্যৎ নিয়ে চিন্তিত হয়ে থাকি।		
3	I have fear of giving birth to another such child এ রকম আরেকটি সন্তানের জন্ম দেওয়ার ভয় হয় আমার।		
4	I cannot accept my child’s disability. আমি আমার শিশুর অক্ষমতাকে মেনে নিতে পারি না		
5	I feel embarrassed about my child's behaviour আমি আমার সন্তানের আচরণ সম্পর্কে বিব্রত বোধ করি		
6	I feel sad having such child in family আমি পরিবারে এমন সন্তান পেয়ে দুঃখ বোধ করি		

III	Physical Problems	Yes	No
1	My child never looks after her/himself independently আমার সন্তান কখনও স্বাধীনভাবে তার নিজের দেখাশোনা করতে পারেনা		
2	I feel fatigue to look my son’s needs and household work আমি সন্তানের চাহিদা এবং পরিবারের কাজ দেখতে ক্লান্তি অনুভব করি।		
3	We have no one to share our child's responsibility আমাদের সন্তানের দায়িত্ব ভাগ করে নেবার কেউ নেই		
4	My ward has no transport from home to school and back আমার সন্তানের বাড়ি থেকে স্কুল যাওয়া এবং ফেরার জন্য কোন পরিবহন ব্যবস্থা নেই		
5	Our IDD child never allows us to sleep till he/she sleeps আমাদের IDD সন্তান না ঘুমানো পর্যন্ত আমাদের কখনই ঘুমাতে দেয় না		
6	I find it difficult to get him/her to do things for him/herself তাকে নিজে থেকে কিছু কাজ করানোর জন্য আমাকে অনেক কষ্ট করতে হয়		
7	I have no leisure to look after myself আমার নিজের খেয়াল রাখার কোনো ফুরসত নেই		
8	I have to carry him/her, wherever I go anywhere আমি যেখানেই যাই না কেন তাকে নিয়ে যেতে হয়		
9	I find very difficult to change naps during her menstruation আমার কন্যার মাসিকের সময় প্যাড পরিবর্তন করা খুব কঠিন হয়।		
IV	**Social Problems**		
1	I feel shameful if someone points about my child's condition or behaviour কেউ যদি আমার সন্তানের অবস্থা বা আচরণ সম্পর্কে কিছু বলে তবে লজ্জা বোধ করি		
2	Our IDD child removes clothes in front of others আমাদের IDD সন্তান অন্যের সামনে কাপড় খুলে দেয়		

3	My ward has habit of frequent quarreling with other children আমার সন্তানের অন্যান্য শিশুদের সাথে ঘন ঘন ঝগড়া করার অভ্যাস আছে		
4	My ward takes others' possessions without their permission আমার সন্তান অনুমতি ছাড়া অন্যের জিনিষ নিয়ে নেয়		
5	Our neighbours ill-treat our child আমাদের প্রতিবেশীরা আমাদের সন্তানের সাথে খারাপ ব্যবহার করে		
6	Other children dominate and tease my IDD child that puts restriction on social life অন্যান্য শিশুরা আমার সন্তানের উপর রোয়াব জমায় এবং শিশুটিকে জ্বালাতন করে যা তার সামাজিক জীবনে বাধার সৃষ্টি করে		
7	I feel fear of discloser of my IDD child's condition as it may affect his/her future আমি আমার সন্তানের অবস্থা প্রকাশে ভয় পাই এই ভেবে যে যদি তা তার ভবিষ্যতের উপর প্রভাব ফেলে		
8	It hurts me, if someone indulges about my child's disability যদি কেউ আমার সন্তানের অক্ষমতার কথা বলে তা আমাকে কষ্ট দেয়		
V	**School and Vocational Problems**	**Yes**	**No**
1	Are you aware of services that are available for him/her তার জন্য উপলব্ধ পরিষেবা সম্পর্কে আপনি কি সচেতন ?		
2	My IDD child's bchaviour may affect the other children in school আমার বাচ্চার আচরণ স্কুলে অন্যান্য শিশুদের প্রভাবিত করতে পারে		
3	I feel fear whether my IDD child may get admission in the school or not আমার IDD শিশু স্কুলে ভর্তি হতে পারবে কি না ভয় হয়।		
4	We do not have proper guidance to train the child at home বাড়িতে শিশুকে প্রশিক্ষণ দেওয়ার জন্য সঠিক নির্দেশনা নেই		

5	I become worried that the child is not upto my expectations in performing daily activities আমি এই ভেবে উদ্বিগ্ন যে শিশুটি প্রতিদিনের ক্রিয়াকলাপ সম্পাদনে আমার প্রত্যাশা পূরণ করছে না		
6	I have no time to attend training programmes for special children বিশেষ শিশুদের প্রশিক্ষণ কর্মসূচিতে যোগ দেওয়ার মত আমার সময় নেই		
VI	**Professional Advice Related Problems**		
1	I feel that I have lack of proper information about child's condition and receive wrong suggestions from others আমার মনে হয় শিশুর অবস্থা সম্পর্কে আমার কাছে সঠিক তথ্যের অভাব এবং অন্যদের কাছ থেকে ভুল পরামর্শ পাই		
2	I believe that doctors had negligence during delivery of my child. আমার মতে সন্তান প্রসবের সময় চিকিৎসকদের গাফিলতি ছিল এটাই আমার বিশ্বাস।		
3	I lost all my hopes about my child. আমি আমার সন্তান সম্বন্ধে সব আশা হারিয়েছি।		
4	I do not have enough time to look after my IDD child and to give training from the professionals in the field আমার হাতে সন্তানকে দেখাশোনা এবং প্রশিক্ষণ দেওয়ার জন্য পর্যাপ্ত সময় নেই		
VII	**Child Management Problems**		
1	Caring and nurturing my IDD child stresses me lot আমার IDD বিশিষ্ট সন্তানের যত্ন করা এবং লালনপালন করা আমাকে পক্ষে অনেক চাপের।		
2	My ward does not perform daily living activities independently আমার সন্তান স্বাধীনভাবে দৈনন্দিন জীবন ক্রিয়াকলাপ সম্পাদন করে না		
3	My child never clear things after activity আমার সন্তান কাজ শেষে জিনিসগুলি কখনই গুছিয়ে রাখে না।		
4	My child does not maintain table manners আমার শিশুটি খেতে বসে টেবিলের শিষ্টাচার বজায় রাখে না		

5	Disciplining and handling my child is a great problem for me আমার সন্তানকে শৃঙ্খলাবদ্ধ করা এবং পরিচালনা করা আমার জন্য একটি বড় সমস্যা		
6	My child does not obey the words and find difficult to make him/her obey আমার সন্তান কথা না মানলে তাকে মানানো কঠিন		
VIII	**Financial Problems**		
1	I find difficult to purchase medicines and materials for his/her development আমার সন্তানের বিকাশের জন্য ওষুধ এবং উপকরণ ক্রয় করা আমার কাছে যথেষ্ট কঠিন		
2	I went for debts for his/her well-being and improvement আমি তার মঙ্গল এবং উন্নতির জন্য ঋণ নিয়েছিলাম		
3	I am not aware of financial support from other resources অন্য কোনো উৎস থেকে আর্থিক সহায়তা সম্পর্কে আমি সচেতন নই		
4	I work for low-wages to maintain for my IDD child’s future and for the family আমি আমার IDD সন্তানের ভবিষ্যতের জন্য এবং পরিবারের খরচ বজায় রাখার জন্য স্বল্প মজুরিতে কাজ করি		
5	I do not have secured job আমার কোন স্থায়ী এবং নিরাপদ চাকরি নেই		
IX	**Psychosomatic Problems**	**Yes**	**No**
1	I suffer with blood pressure and giddiness আমি রক্তচাপ এবং অস্বস্তিতে ভুগছি		
2	I do not have interest to take food and suffered with several nightmares on thinking about him/her আমার খাবার খেতে ইচ্ছে করেনা এবং বাচ্চার সম্পর্কে চিন্তা করে দুঃস্বপ্ন দেখছি।		
3	I got headache for my ward’s condition সন্তানের অবস্থার জন্য আমার মাথা ব্যথা হয়		

Appendix IV

(i) NIMH Family Need Schedule

General Information				
1.	Name of the child			
2.	Name of the Respondent			
3.	Relationship with the child	Mother	Father	
4.	Age			
5.	Education			
6.	Occupation			
I.	**INFORMATION CONDITION**			
Sl. No.	**Need**	**Very much**	**Little**	**No need**
1.	Do you need information about your child's condition or disability?			
2.	Do you need information about assessment reports of your child?			
3.	Do you need information on what you child will be able/not able to do?			
4.	Do you need help in identifying child's present characteristics/features, which may have negative effects in the future?			
5.	Do you need reading materials related to your child's condition			
6.	Do you need information on nutrition/special diet for your child?			
II.	**CHILD MANAGEMENT**			
1.	Do you need information about normal child growth and development?			
2.	Do you need information on how to bring up your child?			
3.	Do you need help to discipline /handle your child			
4.	Do you need help in managing behavioural problems or difficult behaviours in your child?			
5.	Do you need help in getting your child to cooperate in his/her daily activities?			
6.	Do you need to know about what teachers/ trainers are teaching/ training your child?			
7.	Do you need to talk with your child's teacher/ trainer (how often) Daily/Thrice a week/Weekly/Monthly			
8.	Do you need help in deciding to plan for another child			
III.	**FACILITATING INTERACTION**			
1.	Do you need information on how to explain your child's condition to (specify)			
A. Spouse				
B. Other siblings				

Sl. No.	Need	Very much	Little	No need
C. Significant other member in family				
D. Neighbours and friends				
E. Others				
2.	Do you need help to involve others in meeting service needs of your child (specify)			
A. Spouse				
B. Siblings				
C. Grand Parents				
D. Significant other member in family				
E. Others				
IV.	**SERVICES**			
1.	Do you need information on the services that are presently available for you child?			
2.	Do you need help in deciding which training center/school to admit your child?			
3.	Do you need information from where to procure training materials for your child?			
4.	Do you need professionals who could visit your home and train your child (how often) Daily/Thrice a week/Weekly/Monthly			
5.	Do you need information on the effect of admitting your child to special/normal regular school?			
V.	**VOCATIONAL PLANNING**			
1.	Do you need help in finding the most appropriate vocation for your child?			
VI.	**SEXUALITY**			
1.	Do you need information on sexuality issues related to your child?			
VII.	**MARRIAGE**			
1.	Do you need information on marriage issues related to you child?			
VIII.	**HOSTEL**			
1.	Do you need help in deciding whether to admit or not your child in a hostel?			
2.	If you have decided to place your child in a hostel, do you need information which hostel you should admit your child?			
IX.	**PERSONAL-EMOTIONAL**			
1.	Do you need more time to yourself?			
2.	Do you need to talk to someone about your personal problems?			
3.	Do you need help when you are worried, feel sad or depressed?			
4.	Do you need help to manage your physical health problems?			
X.	**PERSONAL-SOCIAL**			
1.	Do you need to have more friends with whom			

	you can discuss/share joys and sorrows?			
Sl. No.	**Need**	**Very much**	**Little**	**No need**
2.	Do you need to meet and discuss with parents having children with similar conditions?			
XI.	**SUPPORT-PHYSICAL**			
1.	Do you need transportation to take your child from home to school/service center/ training center and back?			
2.	Do you need somebody to drop and bring back your child from school/training center/service center			
3.	Do you need someone/worker to look after your child at home? (Specify how often: Daily/ Occasionally/ Part-time/ Full time)			
XII.	**FINANCIAL**			
1.	Do you need financial help to pay for medical care, medicine therapy, or any other services your child needs?			
2.	Do you need financial help to purchase training materials for your child?			
3.	Do you need financial help for meeting any other needs of your child? (Specify)			
A.				
B.				
C.				
D.				
XIII.	**FAMILY RELATIONSHIP**			
1.	Do you need help in discussing family problems and finding solutions? (Specify)			
A. With spouse				
B. Parent child				
C. Between siblings				
D. With other significant family members				
2.	Do you need information on how your child with mental retardation could effect other children			
XIV.	**FUTURE PLANNING**			
1.	Do you need help in financial planning for your child's training and vocational aspects?			
2.	Do you need information on how to transfer your property/savings accounts/pensionary benefits to your child after your death?			
XV.	**GOVERNMENT BENEFITS AND LEGISLATION**			
1.	Do you need information on various government benefits for persons with mental retardation and their families?			
2.	Do you need information on the legislation for persons with mental retardation?			

(ii) NIMH Family Needs Schedule (Bengali Version)

পারিবারিক প্রয়োজনীয়তা সূচী

সাধারণ তথ্য				
1	বাচ্চার নাম			
2	উত্তরদাতার নাম			
3	বাচ্চার সাথে সম্পর্ক	মাতা	পিতা	
4	উত্তরদাতার বয়স			
5	উত্তরদাতার শিক্ষা			
6	উত্তরদাতার পেশা			
I	**তথ্য সম্পর্কিত স্থিতি**			
ক্রমিক নং	**প্রয়োজন**	**অনেক বেশি**	**সামান্য**	দরকার নেই
1	আপনার কি আপনার সন্তানের শারীরিক অবস্থা বা শারীরিক অক্ষমতা সম্বন্ধে তথ্যের প্রয়োজন আছে?			
2	আপনার কি আপনার সন্তানের মূল্যায়ন রিপোর্ট সম্পর্কে তথ্যের প্রয়োজন আছে?			
3	আপনার কি আপনার সন্তান কী করতে পারবে/পারবে না সে সম্বন্ধে তথ্যের প্রয়োজন আছে?			
4	শিশুর বর্তমান বৈশিষ্ট্য/ গুণাবলী যেগুলির ভবিষ্যতে নেতিবাচক প্রভাব পড়তে পারে সেগুলি শনাক্ত করার জন্য আপনার কি সাহায্যের প্রয়োজন আছে?			
5	আপনার কি সন্তানের শারীরিক/মানসিক অবস্থা সম্পর্কিত পড়ার উপকরণ প্রয়োজন আছে?			
6	আপনার কি বাচ্চার পুষ্টি/বিশেষ ডায়েট বিষয়ে তথ্যের প্রয়োজন আছে?			
II	**শিশু ব্যবস্থাপনা**			
1	আপনার কি সাধারণ শিশুর বৃদ্ধি ও বিকাশ সম্পর্কে তথ্যের প্রয়োজন আছে?			
2	আপনার কি এই বিষয়ে তথ্যের প্রয়োজন আছে যে কীভাবে আপনার সন্তানকে বড় করতে হবে?			

ক্রমিক নং	প্রয়োজন	অনেক বেশি	সামান্য	দরকার নেই
3	আপনার বাচ্চাকে শৃঙ্খলাপরায়ন/ সামলানোর জন্য কি আপনার সাহায্যের প্রয়োজন আছে?			
4	আপনার কি আপনার বাচ্চার আচরণগত সমস্যা বা কঠিন আচরণগুলি ব্যবস্থাপনায় সহায়তার প্রয়োজন আছে?			
5	আপনার কি আপনার সন্তানকে তার দৈনন্দিন কাজকর্মে সহযোগিতা করার জন্য সাহায্য প্রয়োজন?			
6	আপনি কি শিক্ষক/ প্রশিক্ষকরা আপনার সন্তানকে কী শিক্ষা/প্রশিক্ষণ দিচ্ছেন জানতে চান?			
7	আপনি কি আপনার সন্তানের শিক্ষক/ প্রশিক্ষকের সাথে কথা বলতে চান?(কতবার? - দৈনিক/সপ্তাহে তিনবার/সাপ্তাহিক/মাসিক)			
8	আপনার কি আরেকটি শিশু নেওয়ার পরিকল্পনা করার সিদ্ধান্ত নিতে সাহায্যের প্রয়োজন?			
III	**সহযোগিতামূলক মিথস্ক্রিয়া**			
1	আপনার কি এই ব্যাপারে তথ্য প্রয়োজন যে আপনি আপনার সন্তানের অবস্থা কিভাবে অন্যজনকে ব্যাখ্যা করবেন? (নির্দিষ্ট করে বলুন)			
ক) জীবন সঙ্গী				
খ) অন্য ভাই-বোন				
গ) পরিবারের উল্লেখযোগ্য অন্যান্য সদস্য				
ঘ) প্রতিবেশী এবং বন্ধু				
ঙ) অন্যান্য				
2	আপনার কি আপনার সন্তানের সেবামূলক চাহিদাগুলোকে পূরণ করার জন্য অন্যদের যুক্ত করতে সাহায্যের প্রয়োজন আছে? (নির্দিষ্ট করে বলুন)			
ক) জীবন সঙ্গী				
খ) অন্য ভাই-বোন				
গ) দাদু-ঠাকুমা				
ঘ) পরিবারের উল্লেখযোগ্য অন্যান্য সদস্য				

ক্রমিক নং	**প্রয়োজন**	**অনেক বেশি**	**সামান্য**	দরকার নেই
ঙ) অন্যান্য				
IV	**সেবা**			
	আপনার কি আপনার সন্তানের জন্য বর্তমানে উপলব্ধ পরিষেবা সম্পর্কিত তথ্যের প্রয়োজন?			
	আপনার কি আপনার সন্তানকে কোন্ প্রশিক্ষণ কেন্দ্র/স্কুলে ভর্তি করবেন সে ব্যাপারে সিদ্ধান্ত নেওয়ার জন্য সাহায্য প্রয়োজন?			
	আপনার কি আপনার সন্তানের জন্য কোথায় থেকে প্রশিক্ষণ উপকরণ সংগ্রহ করবেন সে ব্যাপারে তথ্য প্রয়োজন?			
	আপনার কি বিশেষজ্ঞের প্রয়োজন যারা আপনার বাড়ি এসে আপনার সন্তানকে প্রশিক্ষণ দেবে? (কতবার) দৈনিক/সপ্তাহে তিনবার/সাপ্তাহিক/মাসিক			
	আপনার কি আপনার সন্তানকে বিশেষ/সাধারন বিদ্যালয়ে ভর্তি করার প্রভাব সম্পর্কিত তথ্য প্রয়োজন?			
V	**বৃত্তিমূলক প্রশিক্ষণ**			
1	আপনার কি আপনার সন্তানের জন্য সবচেয়ে উপযুক্ত পেশা খুঁজে পেতে সাহায্য প্রয়োজন?			
VI	**যৌনতা**			
1	আপনার কি আপনার সন্তানের যৌনতা বিষয় সম্পর্কিত তথ্য প্রয়োজন?			
VII	**বিবাহ**			
1	আপনার কি আপনার সন্তানের বিবাহ সংক্রান্ত বিষয়ে তথ্য প্রয়োজন?			
VIII	**ছাত্রাবাস**	**অনেক বেশি**	**সামান্য**	দরকার নেই
1	আপনার কি আপনার সন্তানকে হোস্টেলে ভর্তি করবেন কিনা সে ব্যাপারে সিদ্ধান্ত নিতে সাহায্যর প্রয়োজন?			

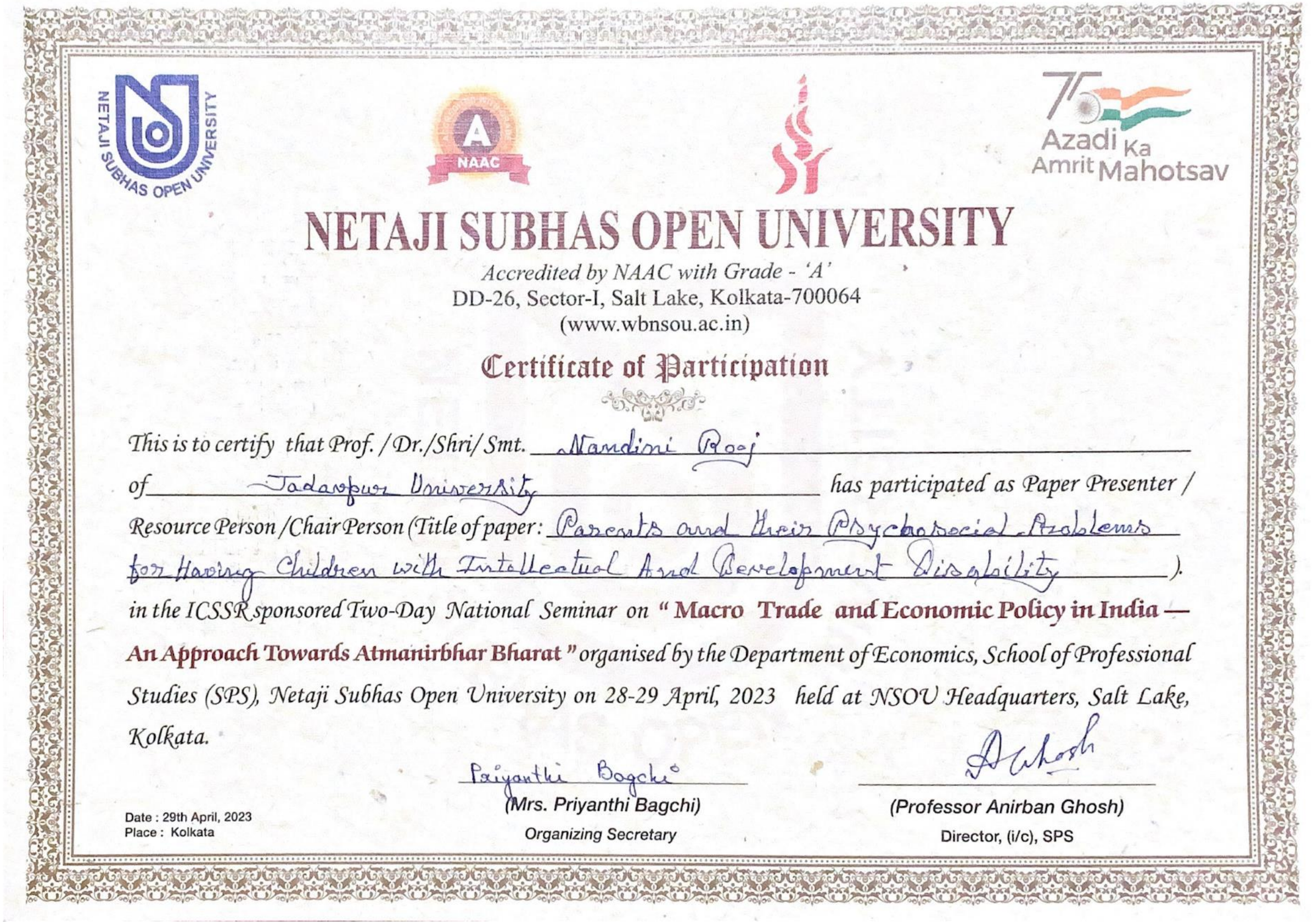
ক্রমিক নং	প্রয়োজন	অনেক বেশি	সামান্য	দরকার নেই
2	আপনি যদি আপনার সন্তানকে হোস্টেলে ভর্তি করবেন সিদ্ধান্তে নিয়েছেন তাহলে কোন্ হোস্টেলে আপনার সন্তানকে ভর্তি করা উচিত সে ব্যাপারে কি আপনার তথ্য দরকার?			
IX	**ব্যক্তিগত-আবেগিক**			
1	আপনার কি নিজের জন্য আরো সময় প্রয়োজন?			
2	আপনার কি ব্যক্তিগত সমস্যা সম্পর্কে কারো সাথে কথা বলার প্রয়োজন আছে?			
3	আপনি যখন চিন্তিত, দু:খিত বা বিষণ্ণ অনুভব করেন তখন কি আপনার সাহায্য প্রয়োজন?			
4	আপনার কি নিজের শারীরিক স্বাস্থ্য সম্পর্কিত সমস্যাগুলি ঠিক করতে সাহায্য প্রয়োজন?			
X	**ব্যক্তিগত-সামাজিক**			
1	আপনার কি আরও বন্ধু দরকার যাদের সাথে আপনি আপনার সুখ-দুঃখের কথা আলোচনা/ভাগ করতে পারেন?			
2	আপনার কি আপনার বাচ্চার অনুরূপ অবস্থার বাচ্চার বাবা-মায়ের সাথে দেখা করা এবং আলোচনা করা দরকার?			
XI	**শারীরিক সহযোগ**			
1	আপনার সন্তানকে বাড়ি থেকে স্কুল/সেবা কেন্দ্র/প্রশিক্ষণ কেন্দ্র নিয়ে যাওয়া, ফেরত আনার জন্য আপনার কি পরিবহন প্রয়োজন?			
2	আপনার সন্তানকে বাড়ি থেকে স্কুল/সেবা কেন্দ্র/প্রশিক্ষণ কেন্দ্র নিয়ে যাওয়া, ফেরত আনার জন্য আপনার কি কোন ব্যক্তির প্রয়োজন?			
3	আপনার সন্তানকে বাড়িতে দেখাশোনা করার জন্য কোন ব্যক্তির দরকার আছে? (কতবার নির্দিষ্ট করুন: দৈনিক/মাঝে মাঝে/ খণ্ডকালীন/ পূর্ণকালীন)			

XII	**আর্থিক**			
ক্রমিক নং	**প্রয়োজন**	**অনেক বেশি**	**সামান্য**	দরকার নেই
1	আপনার কি আপনার সন্তানের চিকিৎসার জন্য বা যত্ন/ঔষধ থেরাপি বা অন্য কোন পরিষেবার জন্য আর্থিক সহায়তা প্রয়োজন?			
2	আপনার কি আপনার সন্তানের প্রশিক্ষণ উপকরণ কেনার জন্য আর্থিক সাহায্য প্রয়োজন?			
3	আপনার কি আপনার সন্তানের অন্যান্য চাহিদা পূরণের জন্য আর্থিক সাহায্য প্রয়োজন? (নির্দিষ্ট করুন)			
ক)				
খ)				
গ)				
ঘ)				
XIII	**পারিবারিক সম্পর্ক**	**অনেক বেশি**	**সামান্য**	**দরকার নেই**
1	আপনার কি পারিবারিক সমস্যা আলোচনার জন্য এবং সমাধানের জন্য সাহায্য দরকার? (নির্দিষ্ট করুন)			
ক) জীবনসঙ্গীর সঙ্গে				
খ) অভিভাবক-সন্তান				
গ) ভাই-বোনের মধ্যে				
ঘ) পরিবারের উল্লেখযোগ্য অন্যান্য সদস্যের সঙ্গে				
2	আপনার বৌদ্ধিক এবং বিকাশগত অক্ষম বাচ্চা কিভাবে অন্য বাচ্চাদের প্রভাবিত করতে পারে সে বিষয়ে কি আপনার তথ্য প্রয়োজন?			
XIV	**ভবিষ্যত পরিকল্পনা**			
1	আপনার কি আপনার সন্তানের প্রশিক্ষণ এবং বৃত্তিমূলক দিকের ক্ষেত্রে আর্থিক পরিকল্পনার জন্য সাহায্য প্রয়োজন?			

2	আপনার কি এই বিষয়ে তথ্য প্রয়োজন যে আপনি কিভাবে আপনার মৃত্যুর পরে আপনার সম্পত্তি/সেভিংস অ্যাকাউন্ট/পেনশন সুবিধা আপনার সন্তানকে হস্তান্তর করবেন?			
XV	সরকারী সুবিধা এবং আইন			
1	আপনার কি বৌদ্ধিক এবং বিকাশগত অক্ষম বাচ্চা এবং তাদের পরিবারের জন্য বিভিন্ন সরকারী সুবিধা সংক্রান্ত তথ্য প্রয়োজন**?**			
2	আপনার কি বৌদ্ধিক এবং বিকাশগত অক্ষম বাচ্চাদের জন্য উপলব্ধ বিভিন্ন আইন সংক্রান্ত তথ্য প্রয়োজন?			

Appendix V

Seminar Presentation Certificates



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This is to certify that Prof. / Dr./Shri/ Smt. Nandini Roy *of* Jadavpur University *has participated as Paper Presenter / Resource Person /Chair Person (Title of paper:* Parents and their Psychosocial Problems for Having Children with Intellectual And Development Disability*). in the ICSSR sponsored Two-Day National Seminar on* **" Macro Trade and Economic Policy in India — An Approach Towards Atmanirbhar Bharat "** *organised by the Department of Economics, School of Professional Studies (SPS), Netaji Subhas Open University on 28-29 April, 2023 held at NSOU Headquarters, Salt Lake, Kolkata.*

Date : 29th April, 2023
Place : Kolkata

Priyanthi Bagchi
(Mrs. Priyanthi Bagchi)
Organizing Secretary

A Ghosh
(Professor Anirban Ghosh)
Director, (i/c), SPS

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Indian Council of Social Science Research

Two Day National Seminar on

Inclusive Society for a Sustainable Future

March 29-30, 2023

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Certificate

This is to certify that Dr./Mr./Ms. Nandini Rooj

of Jadavpur University *has participated/chaired a technical session/presented a paper titled* A Study on the Needs of Parents of Children with Intellectual and Development Disability *in the Two-day National Seminar on* ***'Inclusive Society for a Sustainable Future'***.

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Registrar, Aliah University

Prof. Abdur Rahim Gazi
Dean, Faculty of Humanities and Languages, Aliah University

Dr. Jakir Hussain Laskar
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Head, Department of Education, Aliah University

Dr. Minara Yeasmin
Convenor
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Paper 1

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A Study on Psychosocial Problems of Parents Having Children with Intellectual and Developmental Disability

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Abstract
Intellectual and Developmental Disability (IDD), earlier termed as Mental Retardation, is a disability condition that is characterised by having significant limitations in both intellectual functioning and in adaptive behaviour, that covers everyday social and practical skills of a person. In today's society the problem of Intellectual and Developmental Disability has become an alarming issue globally. It has drawn the attention of parents, teachers, professionals and psychologists in both the developed as well as the developing countries. In recent years a sharp increase in the number of studies, on working with parents of Intellectually and Developmentally Disabled children, have been brought out with valuable information. The parents as an agency of socialisation have great impact on the personality development of the child. Raising a child who had Intellectual and Developmental Disability, requires lots of emotional strength, flexibility, time and energy commitment. The parents of Intellectually and Developmentally Disable children have various psychological problems. The present study was aimed to identify various psychosocial problems faced by the parents who have children with Intellectual and Developmental Disability. Twenty (20) parents (mother/father) of Children with IDD were selected through purposive sampling from a child development centre located in Raiganj, Uttar Dinajpur district. Parents Problem Inventory (PPI), developed by Dr. Anju Singh, was used in order to collect the data for the current study. The collected data were analysed by Descriptive Statistics. Result showed that having a child with Intellectual and Developmental Disability (IDD) had huge effect on their parents. Most parents struggled with various psychosocial problems. Most prevalent problems faced by parents were psychological, physical, social, child management, school and vocational problems, profession advice and financial problems. The study also indicated that mothers faced more problems related to psychological, physical, social, child Management and psychosomatic problems, while fathers faced more financial problems, school and vocational problem, and profession advice problems. Conclusion of the study suggested that there was need for early diagnosis, prompt treatment and counselling for psychological problems in parents as well as proper profession advice, and proper information about Govt benefits and legislation's regarding child's welfare and financial help.

Keywords: *Intellectual and Developmental Disability, Psychosocial Problems, Parents of Children with Intellectual and Developmental Disability, Problem of Parents.*

Introduction

It's never been simple to be a parent. There is no compensation for working nonstop for 24 hours a day, 7 days a week. The profession of parenting has no preparation or training, has neither a sick leave nor a casual leave. Parents, who have children with special needs, especially who have children with Intellectual and Developmental Disabilities, must work without receiving a bonus or increment. According to AKKOK (1996), parents of children with Intellectual and Developmental Disabilities must put in more time, effort, and care than they would with children who are not Intellectually and Developmentally Disabled. Parents who are expected to raise the socially adapted child with special needs experience significant physical, social, and physiological repercussions as a result of childhood chronic illness. For the majority of parents, psychosocial problems involving parents and children who have Intellectual and Developmental Disabilities, can be extremely painful. A healthy child with special needs benefits from psychological elements as well as parental effects and familial influences.

When parents discover that their child has a disability, they start on a journey that takes them into a life that is frequently filled with intense emotion, tough decisions, contacts with many different professionals and specialists, and a continuing need for information and assistance. Parents might at first feel lonely and alone, unsure of how to look for knowledge, help, compassion, and support. A differently abled child has a significant influence on the family especially on parents.. Although having a differently abled child child impacts the entire family, the parents bear the most of the burden. They experience a range of issues, including psychological, financial, emotional, and social ones.

Sen and Yurtsever (2007) carried a study on "difficulties experienced by families with disabled children. The primary objective of this study was to identify the challenges faced by families of differently abled children. The findings suggested that the families lacked sufficient information regarding their child's condition. Mothers expressed deep sadness and stated that having a disability child had a negative impact on their social life, job life, and relationships with their families. Families experienced money issues as well.

Intellectual and Developmental Disability (Previously Mental Retardation) is a condition that impairs both intellectual functioning and adaptive behaviour. As per American Association on Intellectual and Developmental Disabilities (AAIDD, 2010), Intellectual and Developmental Disability (IDD) is a disability characterized by significant limitations in both intellectual functioning and in adaptive behaviour, which covers many everyday social and practical skills. This disability condition originates before the age of eighteen (18).

S. K. Mangal (2009) asserted that Intellectual and Developmental Disabilities is a condition or state of mind. It is not a disease or illness of the mind. Instead, it has to do with the subnormal development of the brain or mind. In addition, he stated that Intellectual and Developmental Disabilities is also related to one's inadequate adjustment with the environment. The deficiency may be observed at birth or in early childhood. Intellectual and developmental disabilities may result from both the inherent and external factors.

The presence of a child with Intellectual and Developmental Disability in the family calls for a lot of adjustment on the part of the parents and the family members (Peshawaria & Menon, 1991). It takes so much of resilience and adaptability on the part of the parents to raise a child with Intellectual and Developmental Disabilities. Parents may get overburdened with different medical, caring, and educational duties because the child has special requirements in addition to the regular needs of all children. The parents are inevitably impacted, regardless matter how complex or small the child's special needs are. Maintaining equilibrium in the home requires support from family, friends, the community, or paid caretakers.

Tsai and Wang (2009) investigated the association between caregiver’s strains among mothers with school- aged Intellectually and Developmentally Disabled children in Taiwan. According to the findings, mothers with intellectually impaired children face significant stress and receive insufficient social assistance. Social support and strain had a substantial and unfavourable status, social support and amount of time spent as a caregiver or parent, as well as the dependent degree of daily living activity of Intellectually and Developmentally Disabled children, were strong predictors of caregiver's strain.

Parents with Intellectually and Developmentally Disabled children may experience physical weariness. The level of this exhaustion is typically correlated with the level of care required for their child. Physically, it is much simpler to feed, bathe, move, dress and diaper a newborn than it is to do the same for a person who weighs 70 pounds. The child may require strict medical supervision and may have more doctor's appointments and other healthcare appointments than the average child. In order to prevent accidental self-harm, such as tumbling down stairs or walking into traffic, he might also need to be taken care of. A parent may get physically exhausted as a result of these added duties. A child with Intellectual and Developmental Disability may cost more to raise than a non-disabled child. These costs may be related to transportation, schooling, tutoring, adaptive tools for learning, or medical supplies, equipment, and care. For that parents face financial problems in their life.

In this study, the term "psychosocial problem of parents" corresponds to family problems, psychological problems, physical problems, social problems, financial problems, problems related to profession advice, school and vocational aspect and psychosomatic problems faced by parents of children with IDD.

2. Objective

The primary objective of the current study is to identify various psychosocial problems faced by parents who have children with Intellectual and Developmental Disabilities (IDD).

3. Methodology

3.1. Research Design

A non experimental descriptive research design was adopted by the researcher to conduct the study.

3.2. Sample

The study was conducted on purposive sampling of twenty (20) parents (both mothers and fathers having children with Intellectual and Developmental Disabilities) taken from Shishumangal child development centre in Raiganj, Uttar Dinajpur district. The study included only those parents whose children were diagnosed with mild or moderate level of IDD.

3.3. Tool

Parents Problem Inventory (PPI) tool, developed by Dr. Anju Singh, were employed in the present investigation to collect the information about psychosocial problems of parents of IDD children. 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. Family problem area consists of 10 items, psychological problem area consists of 6 items, physical problem area consists of 9 items, social problem area consists of 8 items, school and vocational problem area consists of 6 items, profession advice problem area consists of 4 items, child management problem area consists of 6 items, financial problem area consists of 5 items and psychosomatic problem area consists of 3 items.

3.4. Procedure for Data Collection

Written approval was taken from concerned authority to proceed for data collection. The researcher personally went to the location selected for the current study and briefed about the nature of her study to the parents of IDD children. Adequate rapport with the parents of IDD children was made at first. The Parent Problem Inventory (PPI) was individually administered on the parents of IDD Children. After getting back the filled questionnaires the investigator examined that respondents have given their answers to each and every question. If any question/item was found unresponsive then the questionnaire was referred back to the respondents again with the request to make their answer on the unanswered items.

4. Data Analysis

The collected data were analysed by Descriptive Statistics (Frequency Distribution and Percentage Count). Frequency Distribution of respondents on the basis of gender and age are presented in Table 1 and Table 2. Distribution of IDD Children according to the level of the disability is shown in Table 3. Data analysis of parents 'problems are presented in Fig. 1.

5. Results and Discussion

Table 1: Distribution of Respondents (Parents) based on Gender (N=20)

Respondents	Frequency	Percentage (%)
Father	6	30
Mother	14	70

Table 2: Distribution of Respondents (Parents) based on Age (N=20)

Age Group	Frequency	Percentage (%)
20-30	5	25
31-40	13	65
41-50	2	10

Table 3: Distribution of IDD Children according to the Level of the Disability

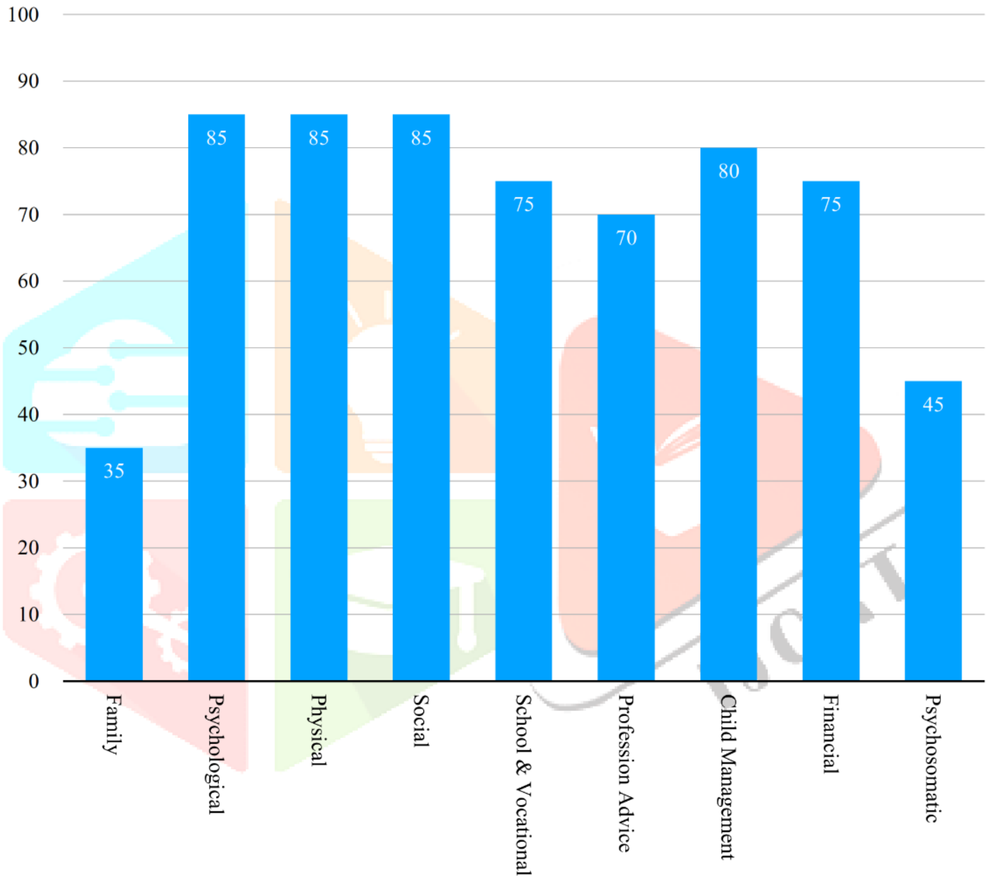
IDD Children	Frequency	Percentage (%)
Mild	12	60
Moderate	8	40

Table 1 and Table 2 show the distribution of parents based on their gender and age. Table 3 shows the distribution of IDD children according to the level of the disability. Table 1 and Table 2 indicate that majority of respondents were mothers (70%) and most of the parents belonged to the age group of 31-40 (65%). From Table 3 it is clear that majority of the parents were having children of mild Intellectual and Developmental Disabilities (60%) followed by 40% of moderate Intellectual and Developmental Disabilities.

The study was designed with the aim to identify various psychosocial problems faced by parents who have children with Intellectual and Developmental Disabilities (IDD).

Fig. 1. shows percentage of responses of parents relating to each of the problem areas in the Parent Problem Inventory (PPI). The top percentage level was observed in the area of psychological, physical and social problems (85%). 80% parents expressed that they face various difficulties related to Child Management.

Fig.1. Percentage Endorsement of Problems of Parents with the help of PPI



The problems related to school and vocation and financial support were expressed by 75% parents. 70% parents expressed their problems regarding profession advice. 45% parents said that they suffer from psychosomatic problems and 35% parents expressed their family problems. Therefore by analysing parents' problems and experiences with the help of PPI tool, the findings of the study indicate that having a child with Intellectual and Developmental Disability (IDD) had huge effect on their parents. Most parents struggled with various psychosocial problems. Most prevalent problems faced by parents were psychological, physical, social, child management, school and vocational problems, profession advice and financial problems. The study also indicated that mothers faced more problems related to psychological, physical, social, child Management and psychosomatic problems, while fathers faced more financial problems, school and vocational problem, profession advice problems.

6. Conclusion

Conclusion of the study suggested that there was need for early diagnosis, prompt treatment and counselling for psychological problems in parents as well as proper profession advice, and proper information about Govt benefits and legislation's regarding child's welfare and financial help. The current study shed some light on the problems faced by parents of children with intellectual disability. Children with Intellectual and Developmental Disabilities are cared for by their parents who serve as their most constant and life-long caregivers. They play a vital and crucial role in shaping the development and life experiences of their children with Intellectual and Developmental Disabilities (IDD). Thus, parents of children with Intellectual and Developmental Disabilities have additional responsibilities and roles in caring for them (Gray, Grove & Sutherland, 2017). They experience various challenges in caring for their children. It is therefore fundamental for all stakeholders with an interest in parents of children with Intellectual and Developmental Disabilities to collaborate and have a better understanding of their challenges. Healthcare professionals, especially professional nurses, should take an active role in reducing the burden of care for parents of children with Intellectual and Developmental Disabilities.

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Paper 2

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Parents and Their needs having children with intellectual and developmental disabilities (IDD): An assessment through NIMH- Family Needs Schedule

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Abstract

Parenting a child with disability, whether a child has a physical disability, a learning disability, an emotional difficulty, or a developmental disorder, can require the development of particular skills, such as caregiving or advocacy, as well as a time and energy commitment that may put careers, marriages, and relationships with other children in danger. Researchers have extensively researched parenting over the years. But, in recent years, it has been noticed that this parenting study has placed a greater emphasis on constructive methods. The present study aimed to understand and assess the needs of parents who have children with Intellectual and Developmental Disability. The main objective of the study is to assess the needs of parents having children with Intellectual and Developmental Disability. Twenty parents (both mother and father) were included in the study as sample from Shishumangal child development centre in Raiganj, Uttar Dinajpur district. The assessment was done by using NIMH-Family Needs Schedule (Parents) to measure needs of the parents. In the present study data were collected by Descriptive Survey method. The collected data were analysed by descriptive statistics and percentage count. The result of the study indicated that the majority of parents showed strong needs in the domain of information condition, child management, services available for their child, Govt benefits and legislation, financial needs, vocational planning, personal-emotional and personal-social relationships. Parents showed less expected needs towards the sexuality, marriage and hostel related information. Mothers showed more needs in the domain of child management and information condition; while fathers expressed needs in the domain of financial help, vocational planning and Govt benefits. This study contributes to a better understanding of parents' needs from their perspectives, as well as their descriptions of the strengths and gaps of the present system. A deeper comprehension of parents' demands could help communities execute government policies and service models more effectively and provide financial assistance to families with poor socioeconomic status.

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Keywords: Children with Disability, Intellectual and Developmental Disability, Parents of Children with Intellectual and Developmental Disability, Needs of Parents, NIMH-Family Needs Schedule

Introduction

Disability in children causes a variety of needs in parents, which might differ based on the nature of the condition and parental attributes. Parenting a child with disability, whether a child has a physical disability, a learning disability, an emotional difficulty, or a developmental disorder, can require the development of particular skills, such as caregiving or advocacy, as well as a time and energy commitment that may put careers, marriages, and relationships with other children in danger. The term Intellectual and Developmental Disability (IDD), formerly known Mental Retardation, refers to conditions that typically manifest at birth and have an adverse impact on a person's trajectory of physical, intellectual, and/or emotional development.

Mishra (2005) argued that the degree of motivation among owners varies according to the owners' perceptions of challenges and opportunities. Financing is one issue that might have a big impact on the owners' growth motivation. While previous research indicates that small businesses may have access to financing, there appears to be a reluctance among owners to employ external financing (Claessens 2006). As a result of advances in unravelling the development and functionality of the brain and identifying the etiologic basis of Intellectual and Developmental Disability, there has been a significant change in the terminology, placement of the condition, classification, and defining features (Girimaji, 2018). Current approaches view IDD from a developmental perspective and rely on both intellectual abilities and adaptive functioning. According to American Association on Intellectual and Developmental Disabilities (AAIDD, 2010), Intellectual and Developmental Disability (IDD) is a disability characterized by significant limitations in both intellectual functioning and in adaptive behaviour, which covers many everyday social and practical skills. This disability condition originates before the age of 18.

The presence of a child with Intellectual and Developmental Disability in the family calls for a lot of adjustment on the part of the parents and the family members (Peshawaria & Menon, 1991) [6]. Some families cope better with the situation than others (Peshawaria, 1995) [8]. Researchers have extensively researched parenting over the years. But, in recent years, it has been noticed that this parenting study has placed a greater emphasis on constructive methods. Research has indicated that approaches that focus on meeting needs of all members of the family are more effective in helping the family to cope with the situation than approaches that focus only on the child with Intellectual Disability. Identifying and supporting the parents in their efforts to meet the needs of all the family members (including themselves) is one of the most efficient ways of developing parental skills which can enhance the development of all family members. Research has also indicated that greater the number of unmet needs, greater is the number of emotional and physical problems reported by the parents (Dunst & Leet, 1987) [4].

For parents, the birth of a child with Intellectual and Developmental Disabilities is a shock, and they go through antagonistic stages like shock, denial and anger before accepting the child. As a result, they demand specific needs and extra requirements for the child and family for the child's complete growth. The needs of families with children who have intellectual and developmental disabilities are extremely complicated, necessitating the implementation of support programmes specifically for these families. In their study, Bailey et al. (1992) [2] found that the factor structure for fathers was noticeably different from that discovered for mothers. Women stated much greater needs than fathers, primarily in terms of family and social support, explaining to others, and childcare. They generally mentioned having financial needs. For programme planning in early intervention, Bailey and Simeonsson (1988) [3] suggested a collection of needs articulated by families.

In this study, the term "needs of parents" corresponds to needs related to the child's condition, needs related to child management, needs related to the facilitation of interaction, services, emotional and social needs, physical support, financial support, family relationships, future planning, and needs related to government benefits and legislation for parents with children with Intellectual and Developmental disabilities.

With the widespread adoption of the international classification of functioning and disability and health (WHO 2001), which considers a person's functioning and disability as a dynamic interplay between health condition and contextual circumstances, assessment of family needs has become essential. Contextual variables encompass both individual and societal elements, such as sex, age, health issues, upbringing, coping mechanisms, social background, and formal and informal social institutions. Understanding how the nature of needs of parents having children with Intellectual Disability changes over time would enable service providers to design appropriate support services.

2. Objective

The main objective of the study is to assess the needs of parents having children with Intellectual and Developmental Disability (IDD).

3. Methodology

3.1. Research Design

A non experimental descriptive research design was undertaken to conduct the study.

3.2. Sample

The study was conducted on purposive sampling of twenty (20) parents (both mothers and fathers having children with Intellectual and Developmental Disabilities) taken from Shishumangal child development centre in Raiganj, Uttar Dinajpur district. The study included only parents of IDD children belong to the age group of 1-5 years.

3.3. Tool Used

NIMH Family Needs Schedule (NIMH – FAMNS) for parents was used to assess the needs of the parents who have children with Intellectual and Developmental Disabilities. The tool was developed by Peshawaria, Menon, Ganguly, Roy, Pillay and Gupta in 1995. NIMH- FAMNS is a semi structured interview schedule and it is used for the following purposes:

1. To identify needs of the Indian families having individuals with Intellectual Disability.
2. To priorities the needs for family intervention.
3. To objectively evaluate family intervention programme.

The schedule contains 45 items organised into 15 categories, 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.

The area "information condition" consists of 6 items, "child management" area consists of 8 items, "facilitating interaction" consists of 2 items, "services" consists of 5 items, "vocational planning" consists of 1 item, "sexuality" consists 1 item, "marriage" consists of 1 item, "hostel" consists of 2 items, "personal-emotional" consists of 4 items, "personal-social" consists of 2 items, "support-physical" consists of 3 items, "financial support" consists of 3items, "family relationship" area consists of 2 items, "future planning" area includes 2 items and last "Government benefits and legislation" domain consists of 2 items.

3.4. Procedure for Data Collection

Written consent was taken from the Director of Sishumangal to proceed for data collection. Consent was also taken to interview each of the respondents (parents) separately. They were briefed about the nature of the study. Adequate rapport with the parents of IDD children was made initially. The questions included in the schedule were asked in the same sequential manner. Each question was asked in a way that did not influence the responses of parents.

4. Data Analysis

The collected data were analysed by Descriptive Statistics (Frequency Distribution and Percentage Count). Frequency Distribution of respondents on the basis of gender and age are presented in Table 1 and Table 2. Data analysis of parents' needs based on parent variable are presented in Fig. 1.

5. Results and Discussion

Table 1: Distribution of Respondents (Parents) based on Gender (N=20)

Parents	Frequency	Percentage (%)
Mothers	14	70
Fathers	6	30

Table 2: Distribution of Respondents (Parents) based on Age

Age	Frequency	Percentage (%)
20-30	5	25
31-40	13	65
41-50	2	10

Table 1 and Table 2 show the distribution of parents based on their gender and age. The above tables indicate that majority of parents were mothers (70%) and most of the parents belonged to the age group of 31-40 (65%).

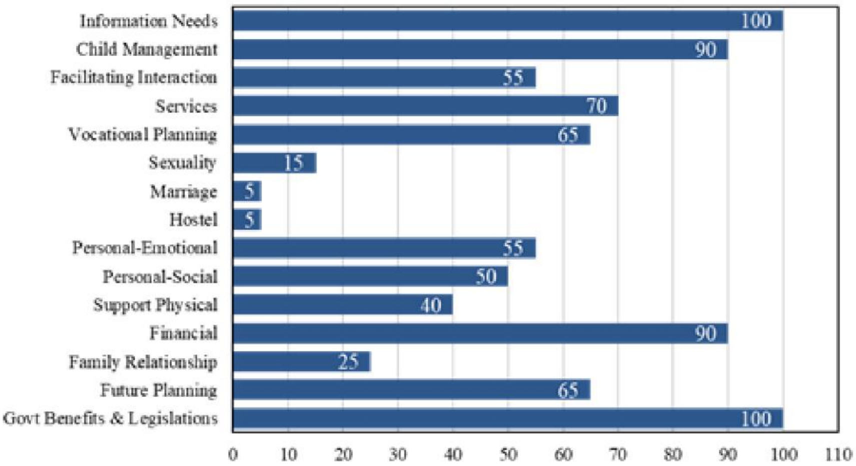

Fig 1: Percentage Endorsement of Needs of Parents

The study was designed to assess the needs of parents having IDD children under 15 domains.

Figure 1 shows percentage of responses of parents relating to each of the domains and needs identified in the NIMH-FAMNS (Parents) Schedule. The top percentage level was observed in the domain of "information-condition" of their child and Govt benefits and legislation (100%). All the parents of Intellectually and Developmentally Disabled Child showed a strong need in the domain of "information condition" and "Govt benefits and legislation". Regarding "information" area parents wanted to know more about the disability condition of their child, assessment report, expected achievement, adverse sequelae, reading material and nutrition of their child. They wanted to know what the Government is doing for the children with IDD and their families which was expressed in the last domain of NIMH-FAMNS Schedule "Govt Benefits and Legislation. 90% parents expressed their strong needs in the domain of "child management" and "financial help". The needs related to "services" (70%), "vocational planning" (65%) and "future planning" (65%) do not however figure as front rank needs. Mostly parents show less concerns in the domain of "personal-social" (50%) and "personal-emotional" needs (55%). It is unquestionably the case for Indian parents that their children come before their own needs, as was aptly demonstrated by the findings of the study. The needs for "support-physical"and "family relationships" were expressed by 40% and 25% parents respectively. The lowest endorsement of needs was expressed in the domain of "sexuality", "marriage" and "hostel" by 15%, 5% and 5% parents respectively. Therefore, by analysing parents' needs with the help of NIMH Family Needs Schedule, the findings of the study indicated that parents having IDD children reported significantly greater needs in the area of information-condition and Govt benefits followed by child management, financial help and services available for their child. The findings of the study also indicated that mothers of IDD children showed more needs in the domain of child management and information condition; while fathers expressed needs in the domain of financial help, vocational planning and Govt benefits.

6. Conclusion

The present study was undertaken with the objective to assess the needs of parents having children with Intellectual and Developmental Disability. Given that parents strongly expressed their needs in the current study, it is necessary to examine the current, primarily child-centred programmes and realign them to address the needs of parents of children with Intellectual and Developmental Disabilities. This study contributes to a better understanding of parents' needs from their perspectives, as well as their descriptions of the strengths and gaps of the present system. A deeper comprehension of parents' demands could help communities execute government policies and service models more effectively and provide financial assistance to families with poor socioeconomic status.

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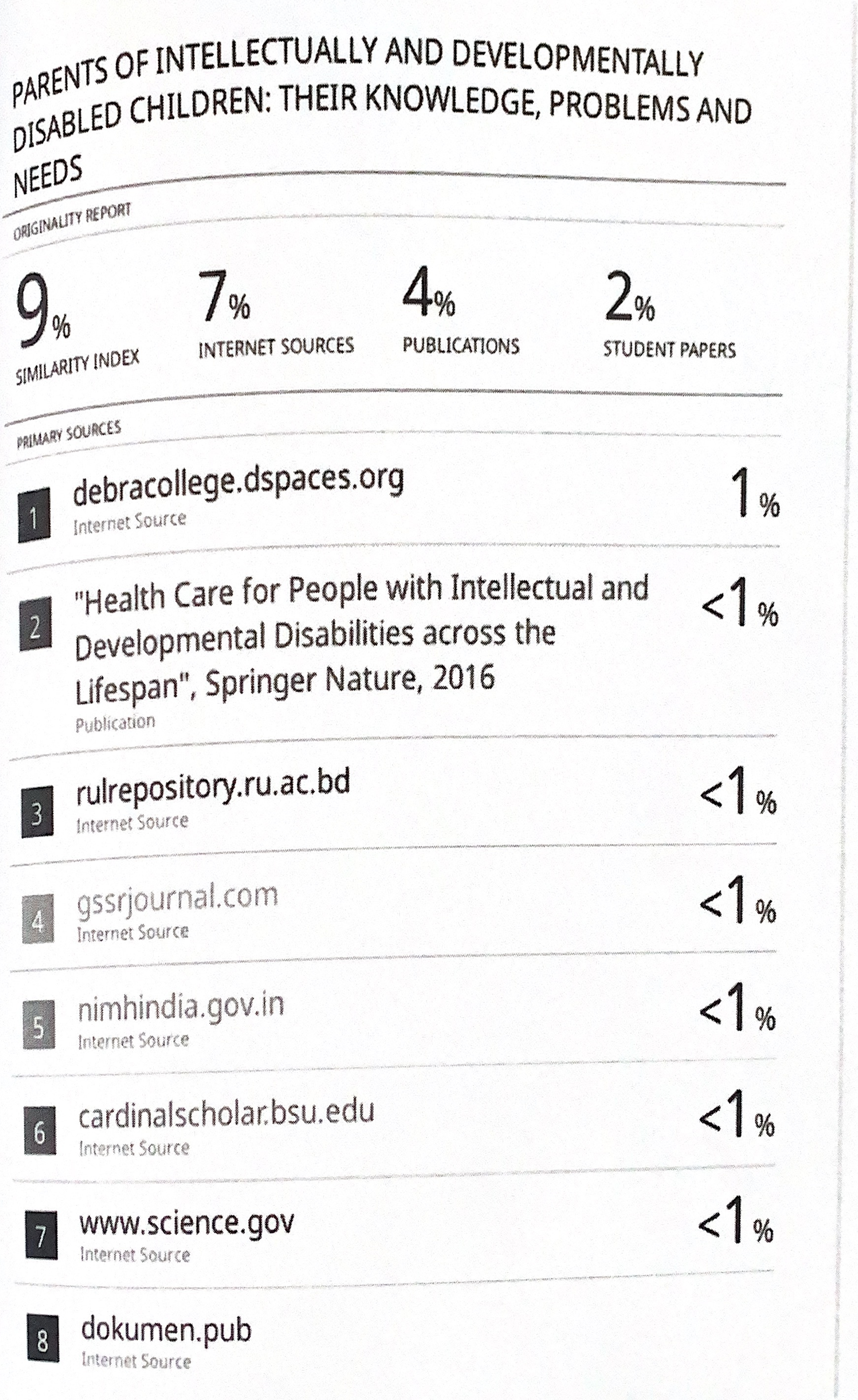
Appendix 7

Plagiarism Test Report



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