

# **LIVED NARRATIVES OF PARENTS OF CHILDREN WITH DISABILITIES**

*A Dissertation Submitted to the University of Kerala in the Partial  
Fulfillment of the Requirements for the Master of Arts Degree  
Examination in Sociology*

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## **DECLARATION**

I, **SRUTHI. S. S** do hereby declare that the Dissertation Titled **LIVED NARRATIVES OF PARENTS OF CHILDREN WITH DISABILITIES** is based on the original work carried out by me and submitted to the University of Kerala during the year 2021-2023 towards partial fulfillment of the requirements for the Master of Arts Degree Examination in Sociology. It has not been submitted for the award of any degree, diploma, fellowship or other similar title of recognition before any University or anywhere else.

Thiruvananthapuram

18/08/2023

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## **CERTIFICATION OF APPROVAL**

This is to certify that this dissertation entitled **LIVED NARRATIVES OF PARENTS OF CHILDREN WITH DISABILITIES** is a record of genuine work done by Ms.SRUTHI.S.S Fourth semester Master of Sociology student of this college under my supervision and guidance and that it is hereby approved for submission.

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## **ABSTRACT**

The journey of parenting children with disabilities is a profound and multifaceted experience that presents unique challenges and opportunities. This study aims to delve into the lived experiences of parents who are raising children with disabilities, uncovering the difficult layers of their daily lives, emotional landscapes, and the strategies they employ to navigate a society that often falls short in understanding their needs.

Despite advancements in awareness and inclusivity, parents of children with disabilities continue to face a range of hurdles that impact their well-being, family dynamics, and interactions with various societal structures. These challenges include inadequate accessibility to educational resources, limited social support networks, financial strains from medical expenses, and the emotional toll of advocating for their children's rights within complex systems.

This study seeks to answer the following questions:

What are the challenges faced by parents of differently abled children in the process of Socializing the differently-abled children?

What coping strategies do parents employ to manage the challenges they encounter?

By examining these questions, this research intends to contribute valuable insights that can inform policy decisions, community support initiatives, and foster a deeper sense of empathy and understanding for parents who are central to the lives of children with disabilities.

The study employed a qualitative research strategy wherein 7 cases were thematically analyzed. The present study concluded that disabled children face many challenges. The number of disabled girls is higher than boys. The institutions provided for the protection of Differently abled children may need many infrastructure facilities, financial assistance, caring Special school teachers, etc., the Mother Theresa Day Care Centre in is a special school Fully working for the welfare and rising of differently abled children.

## CHAPTER I

### INTRODUCTION

Family is the basic unit of social security for every individual, old or young, male or female, healthy or sick, able-bodied or disabled. In families having persons with a disability (physical or mental), the needs and responsibilities of the family increase manifold. In the past, parents were usually advised to institutionalize their mentally retarded child, but it is not practiced anymore. The goal envisaged for the child with mental retardation is to stay in the family and take part in the community. The family environment is also very important to the child's welfare and development.

Differently abled children's means child with mental retardation, hearing impairments (including deafness) speech or language impairment, visual impairment (including blindness) serious emotional disturbance, orthopaedic impairment, autism, traumatic brain injury, disabilities and who by reason thereof, need special education and related services.

In India out of the 121-crore population, 2.68 crore persons are disabled which is 2.2 percent of the total population (Census 2011) are males and 44 percent are females. The total population resided in rural areas (1.86 crore disabled persons in rural areas and 0.81 crores in urban areas). In the case of the total population also, 69 percent from rural areas and the rest in urban areas.

A disabled person suffers from the loss of a limb or deformity in physical or mental capability whether due to nature's foul play or an unexpected unfortunate accident. Problems of disabled children vary in time and space. Their problems are multidimensional physical, psychological, social, cultural, educational, and vocational. Each category of disability poses a different set of problems.

Touching the lives of all to ensure their well-being is the basic rule of good governance and development. Targeted interventions are required for the upliftment of people in a disadvantaged position. Education is the powerful instrument of social change and often initiatives upward movement in the social structure. Education is the core of equality and empowerment so, it is important for all. Education is a fundamental human right and is also indispensable in realizing other human rights. Education for all means education for all children. Every child has the right to good quality education. Education for all can be achieved when inclusion in education is promoted.



Inclusive education is concerned with recognizing and realizing the right to education of all children of whatever race, ethnicity, and needs are part of the regular stream and should be treated as normal children. The Person with Disabilities Act, 1995, has placed responsibility on the government to ensure that every child with a disability has access to free education in an appropriate environment till he attains the age of 18 years.

Parenting is a challenging process. The parents and family's role in caring for a child is very essential especially in development, socializing, and protecting the child which is well established across the country. The challenges face by the parents of disabled children's find it difficult to assist their children with the daily task such as feeding dressing, toileting and mobility parents of the mentally disabled are on the constant lookout for out of –home living services as well as day care services, however, there are certain challenges associated with their service. Inexperienced staff and frequently staff turnover are common there might be conflicts between the parents and the staff members regarding how the mentally disabled should have cared for parent's fear that services might discontinue in the future due to policy of funding change or due to behavioural difficulties and complex health needs of their children. However, coping level of parents with physically or intellectually disabled child.

A family's perception of having a child with a differently abled, the characteristics of the family, the family's internal and external resources, and the child's characteristics are all examples of factors that influence the amount of stress family experiences. Coping is the family's attempt to manage or deal with the stress effectively to avoid negative psychological, emotional, and physical consequences. There are also parents that once they realize that their child is mentally challenged, are confronted with many challenges and problems.

Family interaction is of three broad types that are associated with critical outcomes in children. The first is the quality transaction of parents with the child in day-to-day life, where the parents Respond to the child's achievement. The absence of all these often leads to various problems Between their relationships which can cause insecure attachment. The second is the interaction Among the family orchestrated on the child's experiences. The families usually establish a Routine which is an introduction to the child for the provision of developmentally appropriate Toys and play materials, selecting an appropriate childcare setting, arranging play activities, and involving the child in community activities, consistent with his/her interest or even special needs. The third

family patterns of interaction consist of those parental activities relevant to ensuring the health and safety of the child. Providing proper nutrition, minimizing exposure to a toxin, ensuring that immunizing schedules are followed, and protecting the child from injury and violence.

The coping level of the parents with the child diagnosed is likely to change over some time, as there are parents who have negative feelings where they blame themselves and end up with sorrow, sadness, and trouble. The financial burden for social participation may be increasing for the family member who has children with disabilities. There is also convincing evidence that families which include a disabled child are more likely to be marginalized economically. Children with low social-economic status were three times more likely to suffer than children having parents who are professional workers. Parents of disabled children are more likely to work part-time as compared to other parents.

Segregation or isolation is neither good for the learner with disabilities or general learners without disabilities. The societal requirement is that learners with special needs should be educated along with other learners in inclusive schools, which are cost-effective and have sound pedagogical practices (Yadav 2016).

Parenting a child with a disability depends very much on the gender of the parents as parenting is a very challenging task. The family experiences mental health problems themselves which in return will affect their parenting and caring abilities. On the other hand, there is also an impact on siblings which is likely to affect their relationship in many ways which can create a problem where they cannot share their opinions which will affect their contact, affection, and fulfillment.

Caring for a child with special needs may have a considerable impact on the family. The parents of the child are likely to experience increased burden and parenting stress as compared to parents with healthy and normal children. Economic stability and family structure are important determinants in family burden. Single parents will be facing more problems as compared with two parents as the socio-economic disadvantage will add up to the burden of the child's mental disorder. There is also a caregiver burden which will be affecting the family members in the daily life of the family as well as their relationships. The interaction between the parents and the siblings also increases and sometimes even leads to marital conflicts. As parents without a disability have a possible relief of distributing the household task to their children, but one of the

stressors of the parents having children with special needs is that they may continue to care For the child for an extended period, which can be emotionally challenging.

A person with differently-abled are also the most vulnerable section of the society and also Experience worse education and labour outcomes and are likely to have low economic income than the person without differently-abled. They are also found to be less employed unless they are highly educated.

#### DIFFERENTLY ABLED CHILDREN INDIA

In India majority of the youth population has been suffering from single or multiple disabilities for whom pursuing education is a major challenge. Different combinations of structural factors (such as caste, gender, religion, poverty etc) effect the disability more making the survival of people with disability altogether surpass these factors but the broad commonalities that shape the lives of people with disabilities in India transcend these divisions. Their lives are largely marked by poverty and marginalization from mainstream social processes (Bhatia 2018).

In India data on disabled person is collected through the Decennial population census and through NSSO surveys. The census 2011, conducted by the office of the registrar general and census commissioner India is the source for latest data on disabled persons in India. The census 2011 used improved concepts, questions, methodology of canvassing etc. For better collection of information differently abled persons in India. In census 2001 information on five types of disability was collected, while in census 2011 data was collected for eight types of disability.

As per census 2011, in India out of the 121 cr population about 2.68 cr persons are disabled which is 2.21% of the total population. In an era where inclusive development is being emphasized as the right path towards sustainable development, focused initiatives for the welfare of disabled persons are essential. This emphasizes the need for strengthening disability statistics in the country.

The National policy for persons with disabilities (2006) recognizes that persons with disabilities are valuable human resource for the country and seeks to create an environment that provides equal opportunities protection of their rights and full participation on society. To facilitate the national objective there is a need for collection compilation and analysis of data on disability.

A number of international commitments and guidance came into effect in the recent past targeting the welfare of the differently abled persons. India is a signatory to the Declaration on the full participation and equality of people with disabilities in the Asia Pacific region (2000) . India has ratified the UN Convention on the rights of persons with disabilities (2008), India is also a signatory to the Biwako Millennium Framework (2002) for action towards towards an inclusive barrier free and rights based society. The Biwako plus five (2007) further efforts towards an inclusive, barrier free and rights based society for persons with disabilities in Asia and Pacific added the emphasis. The Incheon strategy to” make the right real” for persons with disabilities in Asia and the Pacific (2012) provides the Asian and Pacific region and the world with the first set of regionally agreed disability inclusive development Goals. The Incheon strategy will enable to track progress towards improving the quality of life, and the fulfilment of the rights, of the region’s person with disability. The sustainable development Goals (2015) pledges for 'leaving no one behind'. Recognizing that the dignity of the human being is fundamental the SGDs wish to see the goals and targets met for all nations and people’s and for all segment of society and to endeavor to reach the furthest behind first. The implementation and monitoring of these international commitments demand sound database of disabled persons.

#### PROBLEMS FACED BY DIFFERENTLY ABLED CHILDREN’S PARENTS

Parenting is a process and supporting the physical, emotional and social intellectual development of a child from infancy to adulthood parenting may be defined as purposeful activities aimed at ensuring the survival and development of children. Birth of the child is the happiest moment of the parents, whereas many parents have a mixed feeling of stress and depression. Parenting becomes even more stressful job and becoming the parent of a child with disability becomes even more stressful and experience life more differently than other parents of normal children. Mothers are the primary caregiver as they remain with the child during the treatment and appear to carry more burden and have the feeling that they need to be with the child so that they experience stress related to coping with heavy load of care giving to the child (Moawad 2012).

Parents of children with disabilities cope with the same responsibilities and pressure that other parents face, however one reoccurring theme reported among these parents is the higher amounts of stress they experience, and greater demands made by caring for a child with special needs. The everyday task of feeding, Toileting, traveling and communicating are much more physically and

emotionally demanding for parents who have children with disabilities. Parents of children without a disability have the potential relief of sharing household responsibilities with their children. One stressor for parents who have children with special needs is that they may continue to care for their child for extended periods of time, which can be physically and emotionally draining. The number of parents in the home and family size also seems to be related to the amount of stress experienced by the parents. The presence of older sibling can help take care of the child with special needs and sharing household responsibility appears to reduce stress. Parents and child interactions also influence the degree to which a family who has a child with special needs experience stress. Depending on the child's ability to interact and communication with the parents. Parents may have to adjust their interaction style to meet the needs of their child. When parents correctly identify the meaning of a child's cues, parent child interactions often bring about desired effects and enhance parental feelings of efficiency and competence( pritzlsff 2011).

Parenting takes place in and through complex relationships. A disabled child may well move the focus away from romantic notions to more broad politicized understanding of parenting. In this sense parents may be viewed as occupying a minority group status (partington 2002).

Disability is often considered as a dysfunctional family, such as pathological views which fails to attend to subtle pressure of disablement and their wide reaching influence on the relationship within families. In the social scientific and healthcare research on disabled babies has focused on the perspective of parents, professionals and other adults rather than children. This has had the effect of viewing disabled children through the eyes of adults and ensured that the voices and experience of disabled children have tended to be preoccupied with impairment, vulnerability and dependency and have thus constructed them as burden to the family and community at large. This reliance upon an individual model perspective of disability perhaps explains an over interest with health, social welfare and educational services and a tendency to view disabled children as a homogenous group, denying their sophisticated identities and ignoring the complexities of their families ( Me Laughlin 2008).

#### ECONOMIC BURDEN FACE BY THE PARENTS

Economic and cost of disability are important and difficult to quantify which include direct and indirect cost some born by people with disabilities, their family, friend, employer and some by the

society. Many of these costs arise because of inaccessible environments and could be reduced in a more inclusive setting. Knowing the cost of disability is important not only for making a case for investment but also for design of public programs. People with disabilities and their families often incurred additional cost to achieve a standard of living equivalent to that of non-disabled people. This additional spending may go towards health care services, assistive devices, costlier transportation option, heating, laundry services, and special diet or personal assistance (World Report on disability 2011).

To raise a child with mentally challenged may be more expensive than raising a typical child, as the expenses may occur from medical equipment and supplies, medical care, care giving expenses private education, tutoring, adaptive learning equipment or specialized transportation. Their where caring of the child may for a lifetime instead of 18 years due to which parents has to set aside their money in the trust fund the child's care when they are no longer with child.

Raising a child with special needs involves more of emotional support which may be different for everyone, but as a whole the general contours of experience are the same, which and be intense. Fortunately, there are different ways where one can nurture and advocate for their child while they are still taking care of one's own need.

It is very difficult for their parent who wants to balance their occupation duty and parental duty for their child, as there is likely to have an impact on the family. As these burden is not going to be for a short period but instead it will be there across the child's life. The kind of financial burden faced by the parents may not be the same where there may be a slight difference according to the needs of the child which may include the cost of private teachers, doctors, consultation, specific learning course and other therapies as the children with no problem does not require special attention ( Norman 2005).

MCDD study provides that parents of children with ASDs were more likely to have attended a parent- teacher conference and to have met with the school guidance counsellor than parents of children in the general education population. These parents were also actively involved in helping their children with homework and were generally dissatisfied with the level of communication provided from the school. Children with ASDs who presented with co morbid disabilities had less involved parents as well as parents who were less satisfied with the school. There was a significant

positive correlation found between the level of parent involvement and the level of satisfaction with the school.

The study provides insight into the challenges faced by parents raising children with ASDs and the inherent difficulties in ensuring their children receive the school services necessary to reach their full potential. The need for schools to actively engage parents of children with disabilities is paramount, particularly when developing an individual education program. An engaged parent is more likely to be satisfied with the school, which can reduce the parents stress levels.

### NATIONAL STANDARDS FOR DISABILITY SERVICES

The national standards for disability services will help to promote and drive a nationally consistent approach to improving the quality of services. They focus on rights and outcomes for people with disability. The national standards were first produced in 1993. They have been revised to reflect current language, philosophies and service models, particularly the move towards individualized supports and person- centered service delivered. In 2010 people with disability their family and cares, service providers and advocates provided feedback on the 1993 National standards with comprehensive consultation led by the disability studies and research Center the university of new South Wales. Consultation focused on awareness and use of the standards, language, meaning, relevance and unity.

Based on this feedback the national standards were revised with a draft version tested nationally in 2012. people with disability, family, friends and care givers, service providers, advocacy organizations and quality bodies informed the development of the revised national standards.

### SOCIAL BOYCOTT

It is preventing of Children With Disabilities (CWD) participating in any social events. Even the family members of the disabled often tend to avoid such social gatherings in shame or fear that someone would ask about their family member with disability. Differently abled children are not exposed to any social gathering, nor does our community recognize the need for children's participation. CWDs are not given opportunities in the areas of education, training and employment. Under these circumstances it is natural that the CWDs feel rejected or unwanted in the society.

## DENIAL OF PROPERTY RIGHTS

As per the Indian laws all kith and kin in the family are eligible to get their share of inherited property, but, persons with disabilities are denied these rights. The siblings take responsibility of providing care and they would enjoy the property meant for the person with disability. Families perceive that CWD are incapable of managing their property they are denied of their property rights and made dependent on the able-bodied siblings. Worst of all would be when family members ensure the chronic condition of the disability by denying treatment or other aids so that the siblings enjoy the property.

Decreased marital life prospects due to a disabled member in the family.

In India the elders arranged majority of the marriages. If a family has person with disability, eligible boys and girls finding a prospective spouse is almost next to impossible because of the stigma and the disability being seen as a family illness. There are occasions where they hide the information and after marriage the problems erupt. It is also common a close relative getting pressurized to marry such a person.

Implication on sexuality of a person with disability

Sexual identity is a critical component of overall personality development and self-esteem which matures during adolescence. In this regard as well. There is a strong attitude of over protection toward the disabled child. Parents infantilize disabled children and imply that sex is only for the abled bodied and of no relevance to the disabled. These parental attitudes are transmitted to the child in subtle ways making him or her feel that she or he is inferior and unworthy of love. Parents of CWDs encourage dependence and share the general societal perception of disabled persons as essentially childlike innocent and sexual.

Women with disabilities

Due to differential gender-based role expectations, education is not considered a priority for disabled girls. Dropout rates for disabled girls are higher than for disabled boys. There is an over representation of disabled boys in education both in special and mainstream schools. Parents become more protective and restrictive, especially after a since besides transport difficulties, the danger of sexual abuse and violation looms large. There is also the reasoning that there's little



point investing in a disabled girl's education as they will anyhow never be able to earn. Unfortunately, a girl child with disability is seen as a lifelong burden on the family because marriage is not a realistic option. Hence, it is concluded to be economically unsound to invest in her education or vocational training.

#### Denial of disability

Predominantly in the cases of mental or intellectual disability, the family members are reluctant to accept the disability or refer to it as a physical illness and treatable condition. The pseudo- stigma attached to such disabilities, makes them hide the fact of having a disabled or challenged member at home ultimately leading to social isolation and restrictive behaviours. There is a fear that they would be victims of disgrace and indignity and there by family members lose the status or acceptance they enjoy in the community. This denial becomes a hurdle for early identification and treatment. Such persons would be hidden somewhere, and they expect, unrealistically to overcome the situation without realizing the long-term consequences of such self-imposed denial.

#### DIFFERENTLY ABLED CHILDREN IN KERALA

Universal enrolment of children in schools is fast becoming the norm even in low- and middle-income countries. India has near universal annual enrolment (96%) for age group 6-14 continuously in the last 6 years. Kerala has achieved commendable advances not only in universal enrolment and retention of children in schools, but also in the health status and literacy rate of the general population. Therefore, providing mental health interventions for children (4-18 years of age) in schools itself can ensure universal access to care. Timely provision of mental health interventions not only improves their present mental and physical health, but also improves educational outcomes in the long term. There is a widespread felt need from various quarters like school principals, teachers and others for providing psychological support for school going children in Kerala. This is raised more often in the context of exam related stress and concerns about increasing substance abuse in children. Universal enrolment of children in schools is fast becoming the norm even in low- and middle-income countries. India has near universal annual enrolment 96% of age group 6-14 continuously in the last six years.

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for providing mental health interventions for children (4-18 years of age) in schools itself can ensure universal access to care. Timely provision of mental health interventions not only improves their present mental and physical health, but also improves educational outcomes in the long term. There is a widespread felt need from various quarters like school principals, teachers and others for providing psychological support for school going children in Kerala This is raised more often in the context of exam related stress and concerns about increasing substance abuse in children.

Across the world people with disabilities have poorer health outcomes, lower education achievements, less economic participation and higher rate of poverty than people without disabilities. This is partly because people with disabilities experience barriers in accessing service that many of us have long taken for granted, including health, education, employment and transportation as well as information. These difficulties are exacerbated in less advantaged communities. To achieve the long lasting, vastly better development prospects we must empower people with disabilities and remove the barriers which prevent them participating in their communities getting a quality education finding a decent work and having their voice heard. As per the UN Convention of the rights of the persons with disabilities article 1 person with disabilities include those who have long term physical, mental, intellectual, or sensory impairments may hinder their full and effective participation in society on an equal basis with others. As per the world disability report 2011, about 15% of the population in the world has disability and among them 2 to 4% is suffering from severe disabilities.

In India as per the national census 2011 the disabled population is 2.1 % that comes 226810557 and female male ratio is 58:42. The planning Commission of India in the 11 th five-year plan estimates that 5 to 6 % of the population have disabilities. In India a considerable number of populations are having disabilities. According to the 2011 census in Kerala there are about 761843 disabled persons and the male population is 51.81% and female population is 48.19% . The persons with disabilities deserve proper care, protection, training, employment, and rehabilitation. Accurate and dependable data relating to the disabled population, type of disabilities, rural and urban population, their economic status etc.. Are highly essential for proper planning, family policies, and developing programs in a focused manner at state and local level. Considering the above facts government of Kerala as per GO ( RT) No. 44/2014 dated 16-01-2014 has declared disability census as a special project of the social Security mission. All over India the government

of Kerala is the first state government initiated and started the complete census of disabled population. A special officer has been already appointment for the conduct of the proposed disability census 2014-2015.

### **STATEMENT OF THE PROBLEM**

The term differently abled is sometimes used as a substitute for disabled or handicapped. Differently abled emphasizes the fact that many people with disabilities are quite capable of accomplishing a particular task or performing a particular function, only in a matter that is different from or takes more time than that of people without the disability. On the other hand, differently abled is often criticized as an awkward euphemism and in some cases may be taken as offensively condescending by disabled people themselves. Physical and mental disability is considered a curse in society. The families of such children treat them as a burden. Their families and caregivers also go through a lot of stress and challenges in having a person with a disability at home which ultimately leads to grave discriminatory practices towards these children.

Social attitude and stigma play an important role in limiting the opportunities of disabled people for full participation in social and economic life, often even within their own families. In the cases of mental or intellectual disability, the family members are reluctant to accept the disability or refer to it as a physical illness and treatable condition. Family members of the disabled often tend to avoid social gatherings in fear that someone would ask about their family member with a disability.

The parent having offspring with the physical and intellectual challenge faced by different parents and stress arises among the family member. Daily, day to day once important factor that brings about a lot of problems among the families as many parents are not being able to manage their time effectively. The financial burden is faced by almost all the parents as many parents might give up their working hours to spend more time with their children due to their economic condition affected resulting in to increase in the stress level of the parents which will again affect the upbringing of the child. If a family has a person with a disability, eligible boys and girls finding a prospective spouse are almost next to impossible because of the stigma and the disability being seen as a family illness. Thus, this study in short covers the challenges faced by the family of differently abled children in the process of socializing the differently abled child.

### **SIGNIFICANCE OF THE STUDY**

The educational attainment of the differently abled person's important in improving their living conditions. And the socio- economic conditions of the children's family is also very important to improve their education and skills.

Families are a critical source of support for children with disabilities. Family members absorb the added demand on time, emotional resources, and financial resources. That is associated with having a child with a disability, such as personal and spiritual growth have also been noted. A disability affects each person differently and therefore no two families can have the same experience when it comes to their child's care. The study expects to understand the challenges faced by the parents and seeking to understand the socialization of differently abled children. The challenge skill used by the parents and family members in bringing up their children, as many parents are finding difficulties to cope up with the situation due to which there is a high level of stress among the parents.

## CHAPTER II

### REVIEW OF LITERATURE

The experiences of parents raising children with disabilities are multifaceted and profound, touching upon various aspects of their lives – emotional, social, psychological, and practical. In recent years, a growing body of literature has emerged to illuminate these intricate experiences, shedding light on the challenges, triumphs, and unique perspectives that shape the parenting journey within this context. This section of the study aims to provide an overview of the existing literature, highlighting key themes, trends, and gaps in our understanding of the lived experiences of parents of children with disabilities.

**Mattsons** (1994) Study on disabled students experience of dependence and autonomy in integrated/segreated environments revealed that student with motor handicaps their choice of upper secondary school and how they looked up on their educational and social situation in school. The studies were accomplished by questionnaires and interviews and had made us a comparison of disabled and control students. The students with disabilities all expressed disappointment concerning the possibilities of making their own decision (being autonomous). The study claimed that ‘students with disabilities were subjected to a sort of passivity from the general environment. In an upper secondary school with special resources, they were taken care of by professional helpers and in the general upper secondary school the school influence did not differ much from that experienced by the control group.

**Adamson & Beswick** (2004) showed that it is widely stated that stroke he is the most common cause of severe disability. They aimed to examine whether this claim is supported by any evidence. Methods : they conducted secondary analysis of the office of the national statistics 1996 survey of disability United Kingdom.

**White** ( 1996) noted that a small fraction of rural disabled people in India have access to government or NGO programmes and that the majority are profoundly socially excluded. In poor communities particularly in rural areas, access is likely to be constrained by lack of information, travel costs etc. ESCAP notes that rehabilitation services in the regions developing countries are still inadequate and poorly coordinated and that commuting to rehabilitation centres pauses serious

difficulties for disabled women and girls and is expensive for their families in terms of money time and effort. UNICEF has reported that women and children receive less than 20% of rehabilitation services.

**Tezzoni & Lisa** (2001) observed that roughly 54 million Americans have some disability at older ages are more likely to be disabled than men. Many people with disabilities today live virtually women normal life spans and therefore routine screening and preventive services are essential to their overall quality of care. We used in 1994-1995 National Health Interview Survey (NHIS) with disability. Family resources and healthy people 2000 supplements to examine screening and preventive service use for adult women with disabilities living in the community about 18.4 % of women (estimate 18.28 million) . Disability was associated with higher age adjusted rates of poverty, living alone, low education, inability to work, obesity and being frequently depressed or anxious. Disabled women generally reported screening and preventive services at rates comparable to all women.

**Rebecca & Karan Moore** (2003) argues that the exclusion of disabled people from international development organisations and research reflects and reinforce the disproportionately high representation of disabled people among the poorest of the poor. The paper commences with a brief exploration of the links between impairment, disability, poverty and chronic poverty followed by a discussion of ways in which disability is excluded from development policy. Evidence of the incidence and distribution of disability is then presented. In the final selection, the ways in which different institutions challenge poverty and exclusion among disabled is reviewed survey with evidence of the limited inclusion of disabled people is reviewed. Survey with evidence of the limited inclusion of disabled people within development institution and policies is presented.

**Agarwal**(2009) observed better socio economic status is closely associated with greater utilisation of health care services among older persons. Patel s k states that treatment seeking behaviour of disabled persons dependence not only on socio economic factors but also on cultural factors, area of residence, literacy status, sex etc. Hidray S Z observed that the physical access to health service is a major hurdle for people with disabilities to reach and utilize these services.

**Baquer** (1997) while reviewing the programmes and policy of the government of India and state government in respect of women with disabilities has criticized the manner of functioning of the

state government. Many state governments have not appointed the commissioner on full time to address the problems of people with disabilities.

**Deenadayalan**(1990) has examined the impact of regular employment activities on the building up of morale and self-esteem of orthopedically disabled persons. The case study was carried out in Titan watches, Tamilnadu and the following findings were significant. When an employee with serious physical disability was compared with the employee who was not disabled the production was the same on both cases. The job stability for the handicapped was greater if they were placed properly. However special work arrangements needed to be extended for disabled persons such as raised markets on doorways, lowered work benches or wide doorways for facilitating their physical functioning and these alternatives could not be considered as unreasonable financial considerations.

**Gathwala & Gupta** ( 2004) studied on family burden in mentally handicapped children and concluded that sixty percent of families were severely burdened in relation to the item effect on the physical health of other family members and concluded that physical/ psychological illness and members of the family becoming depressed and weepily. Forty five percent of families felt severely burdened regarding family interaction and had almost ceased to interact with friends and neighbours. Forty percent had family leisure severely affected and they had stopped normal reaction and had frequently abandoned planned leisure with the affected child using up most of the holiday and space time. Thirty five percent of causes had their family routine severely affected, leading to neglect of rest of the family. Only 25% of families felt were severely burdened financially. 20% had postponed planned activity due to financial constraints. Among the different types of disabilities, the prevalence of Locomotor disability is highest in the country. Quality of life and disability limitation is affected by the availability and utility of rehabilitative services. Thus, knowledge of the treatment seeking behaviour will help in implementing successful intervention programmes.

**Ghasi & Lttyerah**(1980) did a comparative study of the personality patterns life satisfaction and problem patterns of orthopedically impaired and normal mail adults and found that the handicapped were less independent less well-adjusted but more satisfied than the able bodied normal. They were also found to have confronted with significantly higher number of problems in the domains of home and psychological and social adjustments.

**Laskar** ( 2010) observed that rehabilitative institutions such as Institute for physically handicapped, Delhi providing specialized care such as occupational therapy or physiotherapy, aids and appliances and psychological counselling services were rarely consulted in the initial few consultations and about 40% patients approached private hospitals or clinics. Further they observed that 68% approached general practitioner for treatment and 39.4% availed the alternative system of medicine. Similarly, Joshi stated that the most popular type of medicine preferred by those who were seeking treatment was Allopathic which was adopted by nearly 92.2% people. The rest 7.7% of the people rely on either Ayurvedic or Homeopathic medicine in the study conducted by sll india Institute of physical medicine and rehabilitation it was observed that out of 100 patients 13 took local/ herbal treatment and 30 approached a physician from alternative system or Allopathy.

**Midgley**(2000) has proposed a two tier social development model for women with disabilities. At the first stage the general policies plans be actuated from government level down to the community levels so that there will be general awareness for addressing the concerns of disability women. Secondly the women with disabilities are provided with self help model like extending loans, training, running self employment ventures etc.. So that they will be sent from oppressive and dehumanizing attitudes of the other people in the society.

**Rao**(1981) reported a study of the handicapped individuals with regard to frustration. Individuals who were rehabilitated by providing them with artificial limbs and were able. To move about freely showed remarkable change in their attitude. They were almost comparable to normal people and they did not suffer from inferiority feelings and any under ego defensiveness at least apparently. Rao reported that in contrast to popular notions the disabled in most cases exhibited a better appreciation of the purpose of life and were better adjusted. They were relatively free from anxiety owing to the fact that they generally came to terms with their disability and set goals which were realistic thus they tended to be more satisfied and happier.

**Sethi** ( 1981) quoted that a physical handicap may in some situations act as a stimulus and a challenge and call forth all the resources of personalities. However, it may be compensated for in other less desirable ways. The dissatisfaction arising from one's personal defects may be lessened by adopting various defense mechanisms such as by disparaging the goal one cannot reach or the activity in which one is inferior or by decrying the merits of the others and the like.



**Ghai & Sen** (1987) in a study concluded that the four groups—the deaf, the blind, the orthopedically impaired, and normal males—were significantly different in the context of deprivation, the blind being the most deprived, followed by the deaf, the orthopedically impaired, and the normal subjects. The four groups also differed significantly in the context of self-esteem, the disabled group showing relatively more negative self-esteem as compared to the normal.

**Halder & Santhoshi** (2009) conducted a study that explores the various constraints faced by orthopedically challenged women in their way towards higher education in Indian society. The tools used for the investigation are the general information schedule (GIS), socio-economic schedule, and interview schedule. The sample consisted of 100 orthopedically challenged women collected on the basis of a situational sampling technique from eastern parts of India. The findings are discussed in relation to the barriers to higher educational opportunities for challenged women in India. The study found that the brute physical or architectural barriers, financial constraints, and the attitudinal barriers have significant influence on higher education of the challenged women. Furthermore, the study also found huge rates of wastage and stagnation at the primary and secondary level of education. The paper concludes by recommending the need for an overall approach for counteracting various constraints that exist in the early level of their education, without which we can hardly dream of higher education of the challenged women in a country like India.

**Nityananda** (2002) conducted a study in the department of physical medicine and rehabilitation, Burdwan medical college and hospital, Burdwan, a rural medical college in West Bengal during the period from January 1993 to December 1993. All locomotor disabled, irrespective of age, sex, and cause, attending the department and medical Board seeking physically handicapped certificates during this period are included in the study. 780 rural-based locomotor disabled are studied to find out the pattern and cause of disability. Males are four times more than females. Paralysis of limb is maximum (55.1%) followed by stiffness of joint (27.7%), loss of limb (11.7%), kyphoscoliosis (2.8%), and others (2.7%). Paralysis affects mainly one lower limb followed by one upper limb, both lower limbs (14.4%), all four limbs (8.4%), one upper and one lower limb (8.1%). Paralysis of limb is mainly due to residual poliomyelitis followed by spastic cases (70%). Stiffness of joint affects mainly foot/ankle followed by wrist and hand, hip, knee, elbow, and other. Main causes of stiffness of joints are congenital deformity and post-traumatic stiffness. Loss of limb is mainly due to post-traumatic

amputation and congenital limb deficiency 14.3% . Upper limb loss is more than lower limb loss. In this study on locomotor disability poliomyelitis is 45% .

**Prasad & srivastava**(1992) Studied the perceptual motor problems of LD and NLD ( Non learning disabled) children in the age range of 5 to 10 years. The results implied that the children who are poor in perceptual skills are also inferior in their academic performance.

**Sharma** ( 1993) attempted to examine the difference in the personality characteristics of the learning disabled and non-learning-disabled children. The study assessed the efficacy of intervention programmes developed specifically for parents, teachers and LD children in improving academic performance and children with varied learning disabilities.

**Swarup & Sharma** ( 1993) studied the effect of cognitive behavioural training on the written syntax of the learning-disabled children in the age range of 10-14 years. The study showed implication in terms of creating and awareness of learning problems in syntax faced by the students in the normal school set up. Further it focused attention on the need for specific instruction, modelling ,immediate feedback in writing tasks and practice in free expressions of writing so that children master the necessary skills.

**Gupta** ( 1996) studied the incidents and nature of learning disabilities at the end of class second and evolved preventive strategies. They reported 7% incidents of learning disability at Grade third level in government primary schools of sehore block of Madhya pradesh. All the subjects identified as LD in a general class showed deficits in Hindi, oral reading and comprehension, written expression and in arithmetic efficiencies were observed in mathematical operations, serialization, visual spatial orientation, auditory sequential memory, concept formation, verbal, numerical, temporal relationship and visual auditory association.

**Aminabevi** (1996) studied the adjustment ability of post graduate physically disabled and abled students, from the college of Dharwad and Belgaum. Physically disabled were adjusted with respect family, emotion, mode and leadership aspects.

**Kamalam**(1996) carried out a study in the primary schools of Tiruverumdur Block ( rural area) in Trichy district. The study focused on the capacity building of the teachers in educating the mild mentally retarded. The teachers gained knowledge about MMR ( Mild mentally Retarded) after training.

**Paranjape** (1996) compared the achievement in language and mathematics of normal and hearing handicapped pupils studying in class fourth standard of five general schools in Pune. Achievement in language was different in children with and without hearing impairment. Sex did not yield difference in performance within the two groups. Hearing impairment students integrated after special schooling and performed better in math than those who were already in the main stream.

**Ramalingam**(1996) conducted a study on development and effectiveness of a strategy training program for cognitive learning ( memory, comprehension and problem solving) among the learning disabled, non learning disabled and slow learners. Results of the study indicated that strategy training had a positive significant effect on the test of cognitive learning among all groups.

**Vaijyanthy & Meera** (1997) studied problems of the learning disabled children in the primary school. The study reported common behaviour and problems faced by LD boys and girls in different types of schools and classes.

**Venkatesan & Hema** (1997) estimated the prevalence of disability and impairments among pre school children in rural areas. They decided the significant socio demographic variables that influenced the prevalence rates of disability among pre school children in rural areas.

**Zaveri** ( 2001) developed an awareness module on inclusive education for students with disabilities for administrators and teachers of general schools. The module was implemented using printed media approach and interactive approach. The results indicated equal effectiveness of both the approaches for creating awareness. The teachers felt inclusion to be desirable but not feasible.

**Kala parasuram**(2006) study on variables that affect teachers attitude towards disability and inclusive education in Mumbai, India revealed that while some of the variables of interest did affect teachers attitude towards disabilities the only variable that affected teachers attitudes towards inclusion was prior acquaintance with a person with a disability.

**Kathleen & Nole** ( 2010) used the interaction with disabled persons scale to explore the attitude of pre service teachers at a large Australian university to people with disabilities. Using structural equation modelling the factor structure of the IDP was tested. The findings reported significant effects for type of course, age, gender, language and frequency of contact the magnitude of these

effects was minimal. It was also found that changes in student teachers attitudes toward disability over a one year general teacher training course were found to be minimal.

**Bagilhole & Chadwick** (1996) are of opinion that the minimal stance taken by the government of United Kingdom may encourage the employees to side line the aspirations and achievements of women with disabilities regarding qualification and employment.

**Emily** (2002) demonstrated culturally appropriate from independent group living to have a beneficial impact on the women levels of sociability and their confidence to venture out in public or to social functions. Living among other women with disabilities and nonjudgmental environment helped in raising self-esteem and in developing social skills. All of the women who resided in the group house felt accepted, sociable, and confident to venture. Together confidence in their abilities was strengthened and they could carry out their business with mutual support. Thus independent and group living helps in social development ( increased sociability, public confidence and the ability to support) and personal development ( improved self-image, independence and professional motivation) . Within gender, widowhood represents another disadvantage.

**Murt** (1980) conducted a study on disability, utilisation, and costs associated with musculoskeletal conditions in United States, in which it was observed that musculoskeletal problems accounted for a total of 3.9 billion in lost productivity costs for employed persons in the work force and for home makers and thus posted significant economic burden.

**Welbourn** (1991) a study found in the wealth ranking exercise results did not suggest that local people consider disabled people to be poorer and concluded that provided that adequate support networks and labour contacts were important in preventing disability from resulting in poverty.

**Emmett & Tony** ( 2006) studied that in general women with disabilities are more discriminated against and disadvantaged than men with disabilities. In the industrialized countries there are consisted, although not necessarily large, gender difference in income, employment and education for people with disabilities. Poverty deprivation magnify these inequalities and can determine access to food care and social inclusion and even threaten survival. Women with disabilities are also at greater risk of physical, mental and sexual abuse, and because of stigmatization have lower marriage prospects. There are more barriers to access and participation for women than for men,

and mothers and caregivers in particular face enormous challenges when rearing children with disabilities or chronic illness, especially with in the context of women headed households and early pregnancy.

**Audinarayana** ( 2002) examined the prevalence of physical disabilities, their differentials and determinants based on the data collected from 750 old persons selected from nine rural and six urban clusters of Tamil nadu state, India. Findings of the study reveal that half of the elderly population in the study area is suffering from one or the other forms of physical disability. Logistic regression analysis shows that the likelihood of physical disability as compared to their rural counterparts. It was also observed that elderly people who below to the higher socio economic class were found to have lesser disabilities. Among the sample elderly people from Tamilnadu state, India slightly less than half of the elderly persons are found to be suffering from one or the other physical disability closely followed by hearing and walking disabilities. Multi variable results suggest that among the elderly, as age advances there is a great likelihood of becoming disabled and thus the net effect of current age on physical disability is very strong.

**Bleck** (1991) has studied the mobility of disabled persons in seven villages near the city of Bangalore. The objective of the study was to determine the influence of medical and environmental factors on muscle- skeletal disabilities leading to handicaps in mobility. The prevalence of Musculo- skeletal disabilities was 0.4% in villages studied. Fifty-one disabled persons below 50 years were identified. This population was compared with the urban population of Bangalore and one significant finding was that the disabled people in rural areas had better mobility compared with their counterparts in urban areas. This was due to the absence of environmental barriers in rural areas. Moreover acceptance of the disabled in the rural community than urban areas provided more employment opportunities. The author suggests that corrective surgery and used of aids and appliances can qualitatively improve the functioning of the disabled so that their activities of daily living may be carried out without much difficulty.

**Bruyer** (2000) has strongly advocated that women with disabilities should take up their rights to approach the appropriate the authorities to do the needful. He emphasizes that independent development and integration of women with disabilities in the main stream of development for which they themselves should come forward to establish their rights.

**Egan & Warrant** ( 1992) has conducted a study of the activities of daily living of the patients who were in bed after hip fracture. Thirteen men and forty eight women ranging between the age group of 65 to 92 years were studied. These patients were subjected to activities of daily living assessments during three days before discharge. The same was repeated after three weeks of discharge. The concordance between pre discharge and post discharge activities of daily life scores were low, but statistically significant. Thirty one patients demonstrated less dependence. The performance of more dependent activities of daily living at home was not related to role loss or depression.

**Aronson & Pemuda** (1990) conducted a study on the relationship between orthopedic disability and perceived social support. They tested the way in which the orthopedic disability affect social support by using path analysis. Hundred patients with mild orthopedic disability were selected for the study. Hypothesis were offered concerning the effect of vulnerability, uncertainty, personality and social resources on perceived social support. Patients were administered measures of social support, severity of disability, conspicuousness, sense of impediment, anxiety and social status. Among the patients an older patient whose disability was not conspicuous and who suffered high anxiety, experienced least support while a younger non – anxious patient whose disability was clearly visible, experienced most support. The patients personality was more important in terms of perceived social support than was the actual disability and the uncertainty of an encounter between an able bodied and disabled person contributed to the perception of less social support by the patient.

**Elliot** (1992) conducted a study on negotiating reality after physical loss. The utility of different reality negotiation strategies among 57% persons who had traumatically acquired severe physical disabilities was examined. It was predicted that a sense of goal directed determination would predict lower depression and psychosocial impairment scores, soon after injury. To meet the demands of rehabilitation and social integration, however it was hypothesized that a sense of ability to find ways to meet goals would predict lower depression and psychosocial impairment among persons who had been disabled for a longer period. The expected interaction was significant in the prediction of psychosocial impairment but not of depression. The sense of pathways was predictive of impairment and depression regardless of the time since injury. The results suggested

that in reality negotiation process, the different components of hope and salient effects on perception of ability to function in social capacities.

**Govindarajan & Ethirajan** (2012) study on locomotors disability in rural population in Tamilnadu. The study found that the locomotors disability was 129 out of 6550 population in the sun centre which was around 1-9% . The study showed that the locomotors disability was more as the age advances. The locomotors disability male were 22/1000 . The causes of locomotors disability were due to acquired causes and congenital causes. Nearly 58% of persons with locomotors disability were without any occupation and 20% were without any occupation and 20% were doing unskilled labour. 54% reported absence of any source of in income. 53% of the persons were married and nearly 35% of the persons were widow and widower.

**Ghai & sen** (1987) in a study concluded that the four groups the deaf, the blind, the orthopedically impaired and normal males, were significantly different in the context of deprivation the blind being the most deprived followed by the deaf, the orthopedically impaired and the normal subjects in the order. The four groups also different significantly in the context of self esteem the disabled group showing relatively more negative selves ass compared to the normal.

**Graham**(2002) dare is reasonably strong evidence that younger age at amputation results in superior walking ability, which is not unexpected given that fitness tend to decrease with age. However this should not be the only factor considered when deciding whether someone would be suitable for provision of prosthesis, as it is still possible for individuals over 90 years of age to walk independently following lower limb amputation.

**Sophie & Usha** ( 2007) conducted a study in Tamilnadu, this study is the first systematic examination of employment out comes across disability status in and agrarian labour market. This study has several finding that are not worthy. Men with disabilities do not appear to have lower wages than men without disabilities. An analysis of the determinants of the probability of employment among persons with and without disabilities suggests that disability may represent a barrier to employment. Only 52.3% of males with disabilities work compares to 79.1% for males without disabilities. The study result suggests that there is an overall gap of 26.8% points in employment rates among men in Tamilnadu. A decomposition of this gap reveals that the gap is not attribute to difference in demographic, human capital, and other observed characteristics between males with and without disabilities.

**Ravindran & karunanithi** (1983) found that the physically handicapped and the normal, when compared in respect of job involvement did not significantly differ from each other. Physically impairment may impose limitations of the person as well as it may reflect limitations imposed on him, because of socially and culturally defined reactions. They found that a higher proportion of households with self reported disabled members were below the poverty line, had total assets, smaller land holding and greater debt than households without disabled members. Disabled people's are estimate to make up 15 to 20 percent of the poor in developing countries. In some communities the disabled are regarded as the most disadvantaged by others in the community., and it is frequently observed that in low income countries, the disabled poor are among the poorest of the poor. A study by ESCAP notes that the difficulties faced by disabled girls can start at birth and that if disabled girls are allowed to survive they can faced discrimination with in the family, receive less care and food and be left out of family interactions and activities. They also have less access to health care and rehabilitation services and fewer education and employment opportunities.

**Raymond** (2001) paper presented at the 14 th annual meeting of the disability studies association, winnipeg, Canada, from the analysis of the both primary and secondary sources, it is readily apparent that disabled women both in India and internationally, have a relatively lower status than do their male counterparts and are thereby less likely to receive and benefit from the provision of rehabilitation services. Within the Indian social context, women are regarded as inferior beings both by able bodies and even disabled men. Being deprived of basic health services at birth and during early infancy, educational opportunities during their childhood, and often genuine love and affection, it is part from surprising that disabled women life in India are characterized by a lack of self dignity and worth. Key problems are the wide spread belief that disabled people are second class citizen within their own society and the gender bias in the provision of rehabilitation services. Key priorities are the need to ensure that rehabilitation services genuinely meet the explicitly stated needs and aspirations of disabled people. To ensure that as far as possible disabled people are engaged in gainful employment thereby making a contribution to the domestic household to address the gender bias with the provision of rehabilitation services, for NGOS to run disability awareness programmes dispelling some of the negative connotations associated with disability.



**Pati** ( 2011) studied about differently abled women issues and challenges the department of health, government of Philippines conducted study on disabled people development in 2004. This study has pointed out that Inaccessibility Or non- availability of health services attribute to prevalence of disabilities among children in age group 0-14 years living in urban slums and rural areas. Another vital cause of disability is the failure of pregnant mother in attaining prenatal checkups. The study has pointed out that the home deliveries conducted by traditional birth attendants caused accidents in many cases which lead to Occurrence of disabilities among new born babies. The study also point out that the pregnant women and the lactating mother's living in not more than 10% of households covered under survey receive iron and iodine supplements which could have prevented a good number of disability conditions at birth. In other words 90% of families failed to provide iron and iodine supplements to pregnant and lactating mothers and expose them to disability prone living environment. The studies conducted on social service and disabilities conclude that lack of access to basic social services including access to hospital or to benefit of government programmes of health, housing, livelihood, public infrastructure among poor is root cause of Occurance of disability in rural religions of India.

**Patel**(2009) studied about an empirical study on causes of disability in India at ph. D level. The results revealed that locomotor disability is the most prevalent type of disability affecting the population of all ages in India. Mental problems are highest among working aged population and visual and hearing disability are highest among the aged population. The study also reveals that mental disability is occurring mainly due to serious illness during childhood, head injury in childhood and pregnancy and birth related causes. Old age, cataract, glaucoma and other eye disease are the main causes for having visual problems while poliyo, injury other than burns other illness, stroke arthritis, cerebral palsy are the main causes of locomotors disability. The study also shows that injury other than burns is a vital cause of having disability in India.

**Jannet & Yarts** (1990) conducted a study on social support for women during chronic illness, the relationship among sources and types of adjustment. The Norbeck social support questionnaire was used for the study. Totally 125 chronically Ill women were selected for the study. Analysis of variance was used to examine the support from four main sources, spouse, family, and others. Patients perceived more support from the partner than from any other source. Friends provided affirmation than family or others. Next to the spouse, patients confided about their illness more to

health care providers, counsellors or religious personnel than to family or friends. Affect affirmation and reciprocity from both the partner and family were associated with less depression, higher marital quality and better family functioning.

**Nidhiya** ( 2012) The state of persons with disabilities in India Susan parish and Roderick Rose this research provides evidence of statewide disparities in the economic wellbeing of the people with disabilities In particular households with individuals with disabilities have up to 14 percent lower average monthly per person spending as compared to families with able members. Similar trends hold when the analysis is disaggregated by gender of the individual with disabilities, however in comparison to families with male adults with impairment those with female adults with disabilities appear to experience no statistically discernible penalty. The burden for families with children with disabilities is higher than that experienced in households with adult male members with impairments. A way to ameliorate the economic wellbeing of people with disabilities in India may rest on improving services at the state level.

## **CHAPTER III**

### **RESEARCH METHODOLOGY**

**TITLE OF THE STUDY:** LIVED NARRATIVES OF PARENTS OF CHILDREN WITH DISABILITIES

#### **RESEARCH QUESTIONS**

##### **GENERAL RESEARCH QUESTION**

- What are the challenges faced by parents of differently abled children in the process of Socializing the differently-abled children?

##### **SPECIFIC RESEARCH QUESTION**

1. How the parents socialize their differently abled children?
2. What was the supporting system that parents' build-up for the socialization of their Differently abled children?
3. What were the challenges faced by the parents while socializing their differently abled Children?

#### **RESEARCH DESIGN**

The research conducted incorporates qualitative research methods to address the research questions. It is a descriptive research design that attempts to understand the challenges faced by the parents in socializing their differently abled children. Qualitative research methodology is appropriate for this research because of Its emphasis on people's experiences and is, therefore, best suited for finding the meanings they place on events and encounters. The inquiry was conducted with the help of a semi-structured interview and open-ended questioning.

#### **SOURCES OF DATA**

For the present study, data were gathered by way of both primary and secondary data collection.

##### **PRIMARY DATA:**

The primary data was collected from parents of children with disabilities.

## **SECONDARY DATA:**

Secondary data was collected from books, journals, and internet sources.

## **TOOLS OF DATA COLLECTION**

Data for the present study were collected using *unstructured interviews*. For this purpose, an *interview guide* was used.

## **DATA COLLECTION**

### **CASES**

In this research, 7 cases were collected by snowball sampling method.

## **DATA ANALYSIS**

While analyzing the data, the researcher had employed thematic analysis. Based on these themes, after presenting and analyzing the data, the researcher discusses them, based on the major specific question of the study. And finally, researcher concludes the same based on her general research question.

## **CHAPTER IV**

### **CASE PRESENTATION AND ANALYSIS**

#### **CASE 1**

Mrs. Binitha, whose age is 49 and she studied up to the ninth class. Her family is a nuclear Family. There are 4 people in the family including a father, mother and two children. She is a Nadar Cristian. She has a terrace house. Her ration card is BPL. They have their health Insurance card. She is a housewife, and her husband is a tailor. Their monthly income is 9000 Rupees. She does not count how much money spends on the child. Yet she has to spend good money on food, medicine, and other things for the child. But from few days the medicine is not Given to the child. The child is taken to the hospital when the child becomes ill. The name of the differently abled child is Jincy, whose age is 20. The certificate issued by the doctor states That the child has a 70 percent mental problem. Also, there is a whole in the heart of the child. It affects the daily life of the child. The child is interested in dancing and coloring. The child Needs help except for small things. While bathing, the child pours water on her own. The child Got tired while cleaning the yard for a while because of a heart problem. She did not allow her Child to wash any clothes because of the health issue. Her eldest child is in the 3<sup>rd</sup> year of her Degree.

According to her, the child tries to interact well with her and it also helps to understand the child. The child only tries to interact with known persons and does not respond to unknowns. The child likes to play with relatives of the child such as her younger brother's children and they are neighbours too. The happiness of the child can see when the child plays with them. The child also becomes happy when she engages with other relatives. The child becomes wordless or silent after answering what unknown persons are asking. When the child tries to interact with others, does not seem that others are holding the child back. The teachers of the special school said that the child must interact with children and others and should play with other children. The changes of the child are occurred due to the help of the younger brother's children. They do not separate the child with them while they are playing or doing any activities and they play together. Then the special schoolteachers said to her that the child should not be isolated while taking the class and the child must have good contact with others, whether playing or talking. Even if she and her child go to other relatives' houses, they are very supportive. The child is taken out if the next of kin have any

necessities or things. Otherwise, they do not take the child outside. When the relatives came home, she tries to teach the child the names of them. The child knows the name of her younger brother's children. The one-child of the brother has married. when the brother's married child came home the child calls her sister as mentioning the name. Standard one to four the child studied in Paraniyam Government School. While studying in Paraniyam School the child would walk out of the class because the child did not have the intelligence to pay attention in class. The teachers of Paraniyam School complained that the other children were paying attention to the child because of this behavior and when the child walk out the other children helps to bring back the child to the class. After happening that several times the teachers of Paraniyam School started to tell that the child should go to a special school. According to that, the child was admitted to special school. At first, they did not know that there was a special school in Trivandrum. Later, a disabled boy came to the child's father's shop with his father to go to a special school by bus. When they asked the father of the boy which school he was going to, then they found out about the special school. That's how she enrolled her child in a special school. It was after enrolling in that school that the child gained a lot of knowledge and change whether to speak or respond. When someone gets angry with the child, the child will react angrily. Love is what the child likes most and the child did not like scolding especially the parents of the child. When she told that us, the child started crying silently. The special school is better than a normal school for taking care of the child. The special school has competitions for sports, organ, painting, coloring, drawing, etc. Her child has also been involved in it. In the special school, the knowledgeable children and less knowledgeable children are divided into sections for this activity. That is, the children who can walk in one class, and another class include the children like lame, who could not walk were seated and told to read and write. She is also concerned about the condition of the child. Because the child is in this condition, she is always thinking about it. She will look after the child as long as she lives. She worried about the future of the child and worried about who will take care of the child after her time. The eldest daughter did not like a marriage because her eldest daughter did not want to leave the sister alone. The eldest child would say that I have to look after my sister. But in her opinion, doing so also ruin the future of the eldest daughter. Her eldest daughter says that after marriage he will not permit her to look at her sister. Any parent who has a child with such a disability has anxiety and tension. They will take good care of the child as long as they live. According to her normal school did not protect the differently abled children accurately. Her older brother's wife's job is teaching and the

teacher had gone to the schools which look after the children. The teacher had told her about the bad conditions of the children, and it was forbidden to take the child anywhere like that. She also does not like to put the child somewhere else. The child is most close to her and the child-like dad and sister also.

She has bought books, coloured pencils, and sketches for the child. Later, a teacher came and gave the child a multi-colored toy which helps her to identify the different colors. The teacher would teach the child exactly all the colors. By the time the teacher went home, the child knew exactly what color it was. Then the child did not pay any attention to it. After that, the child should always take the book and change the pages. Her eldest child looks after the child when she is not at home. The father and mother take care of the child alike. The father of the child would buy whatever his child asked for. She looks after the child well, by buying everything she needs. After going to a special school, the child learns to look after her affairs. But there has not been much improvement in the study. The child is now brushing her teeth without the help of others. Because the teacher said that the child should be helped to brush the teeth first and then alone. If not, the child will always like to want help. So now the child took the brush and Colgate and brush her teeth without the help of anyone. While bathing, she would rub the child's body with soap. After bathing, the child wipes her head with a towel and she would wipe the rest. The child was able to interact well with the children in the special school. All children are one after going to a special school. There are even more disabled children in special schools comparing with the child. The condition of the children brought from the shore area is unbearable and all of the children are in a state where their arms are crooked, their faces are crooked and unable to stand up. The neck of a disabled child near home is not firm. Her child's neck was also not Firm at the time of delivery. The child has undergone treatment at SAT hospital 6 months after giving birth. After that treatment, the child's neck was fixed. At the time of covid-19, they were in distress. The child's father worked in Thiruvananthapuram. He was affected with covid-19 And dismissed from his job. Because, if the work continues there, covid-19 will be spread to Outsiders when they get there. The father of the child is suffering from ailments such as chills, Stones, and sugar. So, they suffered well. The family survived without any problems because She had a Thozhilurappu job and the child's pension. Otherwise, it is not difficult when her husband has a job. Although the child is going to a special school, the child's name has been Added to the Kanjiramkulam Government School also. Teachers have said that if the child Wants to write the SSLC exam, the name of the child should add to the

government school. Thus, the child gets 1100 rupees from the government school in addition to the pension. Then The help is given from the Anganwadi once a year. There is a Scotty at home. They want the Three-wheeler and they are trying to give applications to the government through the school. The child is not currently taking any medicines. She wants to take the child to a Private hospital because the child has a heart complaint. They will not allow the child to have surgery because she is afraid that something will happen to the child. She is ready to give medicines to the child. She wants the child to be taken to the hospital immediately.

She has difficulty managing time. When she goes out to buy things, she leaves the differently abled child with the older child. If the eldest child was not at home, the child would be left at the grandmother's house. The child spends a lot of time eating when they want to go somewhere. The child eats breakfast on his own and at the same time, the child moves from place to place and makes sounds. The child would be silent when an unknown person came home. The child is free at home. It is very difficult to look after the child when she is not well. The child would tell her if the child felt any discomfort. The child was only taken to some functions of close relatives. She never felt that she has no time for her own. She has BP and is taking the pill twice a day. Earlier she was not feeling well at all. She had felt that she could not handle things alone when she was affected by BP. She has a good headache and dizziness even after taking the BP pill. At that time, she seemed to have difficulty doing things for the child. The child tells her needs while she was taking rest because of illness. Otherwise, she had no problem taking care of the child. Then the father of the child should be given food at 10 clock because of illness. When the child's father was drunk, he would say something because of the tension at that time. The father has a good love for the child in total. In some places where there are children like this, the fathers have even left their families. In that sense, the father of the child would say something while only drunk. She does not have to spend a lot of money on her child's education. In special school, she has to pay a fee of 500 rupees. A pair of uniforms should be given from the special school and a pair of uniforms should be taken by her. Then she has to pay a small amount to the school bus and should buy a bag and books for the child. All in all, for the education she would have to pay 1500 rupees. Initially, the child's pension was received late. The pension is received correctly within four to five months after the election. She would open up if she had any problems. She used to tell those close to her about her difficulties. In her opinion, if it was kept in mind in it would be another state of tension. Anything in her mind, she tries to avoid tension. She shares everything with her companions,



whether it is a matter of a differently abled child or an older child. She mostly shares things with her close neighbors. The condition of the house has been a bit worse since covid-19 came. She would have sent the child to school if there is no covid-19. The child does not always go to school. Even when going, it is very difficult for the child to travel by school bus. The child will get sick suddenly. After going to school for two or three days, the child is unable to go to school on another day. This is because the child would get a cold when the child goes to school by school bus after taking a bath in the morning. In the afternoon, the teachers take the child to play with other children when the sun's rays are strong. The child would go home and say all this. The child was not forced to go to school at such times. If the child wants to go, the child's father used to tell the child to stay home. The father had told the child to go to school, whenever the child felt like it. When the child went to school, she could go to the market or the neighborhood freely. classes yet not begun at the special school since covid-19. It has been a year since the teachers saw the children and a function has been conducted in a special school for seeing all the children. But the child does not go to the function because of the thread of covid-19. The child loves to go on tour. She took the child on tour before spreading of covid-19 and suffered a lot. As soon as the child walked a little, the child started to cry because the child has breathing difficulty. At first, the teachers of special schools did not allow the child to use the school wheelchair. At the end of the tour, the HM gave a wheelchair after seeing the worst situation of the child. After that, she was not interested whenever the child talked about the school tour because of the child's condition. The child has participated in up to 3 dances during the school program. Because of the breathing problem the child has suffered a lot in dancing also. After that, she told to the teachers to participate only in fancy dress competitions such as angel, being the flag bearer, etc. teachers scolded her after seeing the condition of the child when the child went on tour. The teachers scolded her because she does Not try to allow the child to walk daily basis. After hearing this, the child started walking Through the small road in front of her house and the child started to recover from the difficulty. The other child's parents would attend all the programs at the special school and their Conditions are even more difficult considering the condition of her child.

## **CASE 2**

Mrs. Sujatha whose age is 48 and she studied up to the 10<sup>th</sup> class. Her family is a single-parent family, and she is a Nadar Christian. There are 4 people in the family including a mother, child,

Mother-in-law, and father-in-law. She has a terrace house. She owned a BPL ration card and They also have Health Insurance Card. Their monthly income is 600 rupees. She does not know How much money to spend on the child. She spends money on the child based on the needs. The name of the Differently-Abled-child is Surya, whose age is 14. According to the certificate, the child has 95 percent of physical issues. The child cannot walk, and her neck is not fixed. There is a lack of strength when the child stands with the help of someone. The child cannot stand well and the child is always sitting in a chair. The child would sometimes hold her hand openly. She would take care of the child while she was at home. Otherwise, the mother-in-law would take care of the child when the mother-in-law does not go anywhere. Everyone was doing the child's things daily. The child cannot do anything on his own. The child would sometimes call her mother and sometimes she seems like the child was calling her. They did not take the child to school after the spread of covid-19. She did not know if there was an online class or if the class had started or not.

The child would understand what everyone is saying. The child would cry and laugh and respond to everything. The child would understand what others say about the child. The child would laugh when after the child was introduced to outsiders. Otherwise, the child did not laugh. No relatives go to her house. She can't go outside because of the child's situation. The child was not taken outside because of the child's situation and the child was not taken outside for several days. When the child was taken outside, the relatives seemed to hold the child back. People go to her house only to study the situation of the differently-abled child. She did not feel much tension because her father-in-law and mother-in-law were at home. The child can do all the basics only with her help, she should give food, and so on. The child was told to do physiotherapy after going to a special school. It was a good change after physiotherapy. With the help of someone else, the child would color the pictures. In the past, the child's body was not strong as in present. Now if the child is put in one place, the child would sit in that position. The child has never been enrolled in another school before. If anyone says things the child does not like, the child would make a sound and get angry. She understands all these things of the child. The child was taken on a tour from the special school. It was nice to see all the places for both child and parent. She and the child did not feel any discomfort when they went on tour. If she had not gone on tour, her sister or mother-in-law would have gone on tour with the child. Everyone in her house is very cooperative. She says that the life of the child will go on according to God's desire. The child is closer to the child's grandmother and also closer to her and other family members.

The child could not participate in any of the competitions held at the special school. There is something wrong with the child's nerve in the brain. She is now unable to take the child to the Hospital. The child was earlier treated at SAT hospital. The medicine is usually given to the Child when only needed. They have financial difficulties. She has been able to establish a good Relationship with the special school. The child has not reluctant to go to a special school and the child loves to go to a special school. The child goes to a special school on the school bus. The child is carried on the shoulder to the bus stop. The child does not own a wheelchair. She Felt that the child needed a wheelchair. The child does not receive any benefits other than a Pension from the government. When she is not at home, her mother takes care of the child. The child is never left alone at home. She has been receiving the child's pension properly for some Time. They have no difficulty in spending money on the child. After going to a special school, the child began to play, laugh, and interact with people. When she must do some work, she could be late to take care of the child. But she put her job aside and try to take care of the child. There are no vehicles in the home. She does not take the child to a relative's functions.

She never felt like that she could not do new or different things after getting a differently abled child. To her, the child is like a friend. She could not do things without the help of other family members. She gives more time to the child. She interacts with other parents when she can. Parents do not always talk. She would tell those who asked about her grief especially for those Who go to study. They have had a hard time since covid-19 came along. The child has to go to School.

### **CASE 3**

Mrs. Sindhu whose age is 40 and she studied up to the 7<sup>th</sup> standard. Her ration card is BPL. They have health insurance cards. She is a housewife, and her husband is a fisherman. Their monthly Income is 1000 rupees. Now the child is not taking any medicine on a large scale. At a young age, the child took a lot of medicine. Now the child does not take any medicine because of its aftereffects. Then they spend money on other things also for the child. The name of the Differently abled child is Nicolas, whose age is 21. The child has mental and physical issues. After the child was born, the child's legs were paralyzed. The child will crawl and will not be able to walk. Then the child's eye had a small problem like squint eye. The child did not remember what others said before. The disability of the child is 60 percent. The child would do whatever the child could do

on his own. Only with the help of someone, the child would be Able to do his basics. The child can only stand up only with the help of someone. Sometimes the child would eat the food on his own. The child would eat the food correctly only when it Was given by her. The child has 2 younger siblings. The second child is studying for a degree in the second year and the third child is in degree in the first year.

The child used to talk to everyone in the house. When strangers go to her home, the child smiles at them. But the boy did not talk to them much. After interacting with them, the child would Talk to them well. But the child will take time to interact with them. She did not feel that the Child had been abandoned by others. The child would be carried in a wheelchair when they go Outside. At that time others on the roadside would ask her that she need any help to take her Child home. The attitude of the people is good, where she lives. Negative experiences did not Affect the child when he was taken out of the house. She would have told the name of others to the child to improve the interaction of the child. She would make the child comfortable talking to others and try to make a connection to their conversation. After going to a Special school, the child improved his ability to fulfill his basic needs and it also helped the Improvement in the child's crawling. The reason for enrolling the child in a special school was That her nephew was going to that special school. The special school Is better than the normal school for taking care of the child. The child's exam was written with The help of a stipend in a normal school. They are going with a good relationship with the Special school. A special school has organized physiotherapy for their children. Each student Would be done some different activities as he could for improving their capability for example beading with a big pearl. The special school organized some activities for mentally ill children also. The special school has competitions like band, coloring, drawing, sports, etc. The child would speak to the neighbors when they came to his home. She has anxiety about her child's future whether the child becomes safe in the future. The child is very close with the family members also with other relatives. He does not stay away from his family and relatives.

She would buy books and crayons for the child to color the pictures and she would help the child to write by hand. CRC teachers go to her house to teach the child also in the covid-19 Period. The teachers also went to her house with teaching materials for the child. The child's Father and siblings take care of the child when she was not at home. She gives more care to the child when the father of the child goes to work but the father takes care of the child also. The Interaction with

the child in the special school has influenced the child and he have a closeness to them. The child wants to go to a special school to see his friends and teachers during covid-19. The child would quarrel for a while because it was unlikely to happen. Forgoing outside of the house with the child they prefer auto-rickshaw to the bus for the safety of the child. The Child receives a pension from the government and a scholarship from a government school. The income they receive is enough to supervise the child. They have no vehicles.

She never felt that she could not control her time to do household chores. If t e child cried or smiled, the child would share his feelings with her. She would take the child to the next of kin's ceremony and it was based on the distance they are going to travel. The behavior of the relatives was very good when the child went to the relative's ceremonies. The child was not separated by relatives due to disability because loves him and is a part of that family. She never felt like that she could not do new or different things after getting a differently-abled- child. She does household works with the help of her husband and siblings and she never felt the need to act alone. She happily spends more time with the child and helps the child to do his activities. It is good to spend more time with the child. The child did not affect her relationship with her husband. They have spent 500 rupees on the education of the child in the special school. She would pay the fees if any programs came up. She would share her worries with other family members like her husband and brothers. During the covid-19 period, she looked after the household chores. The child was sad, during the lockdown period as he could not leave the house. Now she can take the child outside.

#### **CASE 4**

Mrs. Sobha , whose age is 50 and she studied up to the 7<sup>th</sup> standard. Her family is a nuclear Family. She is a LC Makua Christian. They did not have their own house and because of that They change their previous house and started living in a new rent house. After that, she lived in Many rental houses. Now she has rented a house in Pallam. Now the borrowed house is a sheet House that falls off if touched by hand. Her ration card is BPL. They had their health insurance Card, but it has not been updated now. She is a housewife and her husband is a fisherman. Their Monthly income is 1500 rupees. It takes a lot of money to buy the child's medicine. All Medicines and food should cost around 150 rupees a day for the needs of the child. The name of the child is Favisto, whose age is 23. The child cannot speak. But he can understand what others are saying. Occasionally the child was infected by jenny. At first, jenny would come Every day. Discomfort occurs only

occasionally after going to the hospital because of jenny. The child does his own thing every day. She has one daughter and two sons. The boy has completed his degree and her daughter is studying in plus two.

The child was born speechless. The child would wave his hand and call and try to engage with others. Once the child sees someone, it is enough to remember them when they meet again. The child knows well everyone he has seen. When the child eats something solid, it will stick to the head and it would not have been normal for the child until omit everything that he has Eaten. When this happens, the child would show with his hand as he has a headache. Now the child can recognize his illness. Earlier, when the child became ill, the child would fall. As soon as the eyes widened, the child knew he was going to fall. The child would then sit there or lie on her lap. Now the child has no such difficulty as that. When the child was taken out, she did Not feel that others were holding the child aside. She used to take the child to relative's Functions. She would tell the child what to do and what not to do when taking the child to the ceremony. The child would obey it. When someone unfamiliar with the child came home, she Would tell the child their name and relationship with the child. After that, the child would Understand when she said about them. The child once stood in an institution in Vaalakam Kollam. They did not take the child to the hospital when he became ill. Then they called her And told them to take the child back home. So, she took the child home. Besides that, they Abused the little kids there. They would pour tea into the child's hand. After that, she never left the child anywhere. Then they had to stay for two or three months in a place called Uravila. The child was not left in any institution there either. After that, the child stayed at home, and She did not want to leave the child in other institutions. Even if the child was put in any institution, she would go home and cry. Some days she would bring the child back. She said she cannot live without the child. The child is also loving his mother. A special school is good In teaching, cleaning, caring, food, etc., The special school is teaching the children by dividing Them into sections. She has a hard time leaving the child at the bus stop when the school bus arrives because there is only a short way to her house. By the time the child was taken to the Bus stop, the bus was gone. It would have taken a long time to recall the child from the bus Stop. This was the only thing that has bothered her. Her younger sister was a worker in VSS. Her younger sister told her that she knew about special school so she could enrol the child There. Because special school is near the house and the child can go and she can look after the Child if anything comes up. The child is a member of the band set. Neighbour's love the child. The child is especially

close to the child's father. Anxiety about her child is a concern for those who will look after the child when her time is up. She is still worried about her child.

They all buy books and toys for the child. The child receives 12000 as a scholarship in a year. They are not getting any benefits from the Government. She did not go anywhere when the child is alone in the home. When she went outside to purchasing, she took the child with her to the market. They are living now in an unknown place. That's the reason why she frightens to live her child alone at home. She and her husband care for the child equally. The child's Interaction with other special school members helps the child to improve the daily activities. The collaboration of the children is very good in the special school. She did not go through a Barrier while looking after the child. The income is not enough to look after the child. Without The child's father, they are in starvation. The child's father working far away from the house. In the covid-19 pandemic period, it became much more difficult. They did not have their Vehicles. The child is taking medicines two times a day. No compromise in that.

She has difficulties doing all the things. Her husband and other children help her in the household works when they are at home. They give medicine to the child when she is told to Give. Sometimes the child scolds for the remote of the TV. She knows the mood of the child only seeing the face of the child. If not given to the child what the child asking, he told that to Her. When the child understood we are discussing the child he smiled. According to her, the child is God's gift. We cannot refuse it by whitening in a paper. She desires to look after the child until the end of her life. One day the fathers and sisters make a kyamp in Vettukaad. First, she decided to add the child to their school. But other family members are not ready for it. She never felt that the child is affecting negatively the relationship with her husband. They have a debt of 5 lack rupees for buying their own house. They bought books and a bag for the child. To reduce her sorrows, she told her worries to the authors. Before some days she was affected By covid-19. That time she stayed in her mother's house. Now she is fine.

## **CASE 5**

Mrs. Nirmala, whose age is 62 and she studied up to the 8<sup>th</sup> standard. She is an Ezhava Hindu. They have a terraced house. Her ration card is APL. They have a health insurance card. She is a retired Anganvadi helper and her husband did not have a job. The monthly Income of the family is 1000 rupees. It can cost up to 5000 rupees per month for the child. The name of the child is

Revathi, whose age is 32. The child has a mental issue and has a disability of 80 percent. With her help, the child would be able to do small chores around the house. She would clean the yard, bathe on her own, and look after her things. These changes occurred after going to a special school. She has two child's, and the older child is working in the Panchayat.

The child cannot speak fluently. But an outsider cannot identify the child as differently abled. She has not the capacity to store study knowledge in her mind. The child freely talks to those who known earlier and they know about the differentiation of the child. Now a day's society is also considering these kinds of children. So, they did not identify their child separated from mainstream society. These kinds of the child also possess a special role in society. When she Went to functions, the child was also taken. She introduces new relatives to her child who goes to their home. But the child only remembers the names of close relatives. Nevertheless, the Child will be forgotten about the others. The child was studied more in Anganvady and Nursery. After that, the child Studied in an institution that was organized by a father. That's also a daycare center. Then the child went to a boarding school in Vellarada. After going there, the child's daily activities are improved. For Example, in doing household jobs, traveling, and speaking. The special school also provides Physiotherapy for the differently abled child. Her child has also gone through physiotherapy. After doing it the child has small kind of changes. The child loses the opportunity to mingle with normal children by studying in a special school. Earlier the child studied in a normal School. But situations bring the child to a special school. Now the child did not like to go to a normal school. The special school has its school bus. They took the child in the morning and leave the child near home in the evening. The bus has small fees. An event occurred in Sreekariyam named Olympic where the child achieved a second prize on it. The neighbours are Very interested to talk to the child. The visitors all investigate the child. The child smiles at them and wishes them a good day. She also has anxieties about her child. After her who will Look after the child. Is a question mark for them. Thinking about it as a stressful situation. But now they are satisfied with their life with the help of their relatives and Government. The child Is very close to all the family members of the family. The child is very happy with all of them.

She bought and given a bicycle to the child. But the child cannot ride on it. The child plays with small toys. The special school also has toys to play with the children. The Government only provide scholarship for the child which only satisfactory for child's cost. The brother's Wife looks



after the child in the absence of her. She and her husband care for their child equally. The children of the special school have some difficulties. So, they cannot say that the children of special school made a change in her child. It cannot link with their life or development According to her. But the child has a good friendship with the children of special school. The child needs someone's help to cross the road. The child cannot live alone because the child has No that much care. After the covid-19 period, the school was closed. They don't have their vehicle. The child doesn't have medicines daily. The child takes medicines occasionally for allergies.

According to her the child also a member of her family. So, caring for the child is their duty and she doesn't need to find separate time for it. For girl children, they need to give more attention to caring for them. They cannot live their girl child alone in the house or live the child in another home. The child expresses feelings to her like anger and sadness. The child did not hurt anyone. She never felt that she cannot do new things because of the child. She saw the child as a gift from God. She felt like that she cannot do all her works lonely. The child never makes an issue with the relationship between her and her husband. They all live together with friendship and love. She spends money for the child for buying books, bags and pencils and a small fee in the special school. She only shares her worries with others when she realizes they should be shared. Covid-19 period increased their economic difficulties. She also has lungs related diseases, and her husband has gone through the bypass.

## **CASE 6**

Mrs. Bindhu whose age is 41 and she studied up to the 7<sup>th</sup> standard. She is a LC Mukuva Christian. She has a terraced house, and the ration card is BPL. They have their health insurance Card. She is a housewife, and her husband is a fisherman. The monthly income of the family is 375 rupees. The child's daily expenses include fees for school and meals etc. They do not buy Anything special to eat. The child had been taking the medicine earlier but now the child is not taking any medicine. The name of the child is Rojin, whose age is 20. The child has a mental and physical issue of 70 percent. The below the waist of the child is paralyzed. He does the Basics without realizing it and the child also forgets about things. It is difficult for the child to Read. He studied up to plus two, but he did not know to read. The child would copy the text. The child did not know to write on his own. The child would forget what was asked of him Earlier. He is angry with brushing his teeth. The child has no interest to do anything. Earlier They had given coloured pencils to colour the

pictures and the child would color. In lockdown Period teachers would ask the child to write words by watching them on TV. After that, the child would always look at the TV and write the words he sees on TV and the child did not Have an interest in other things. He was not interested to do small works. Everyone would take good care of him. That's why the child did not have any interest to do other things. She has Three sons. The oldest child studied software engineering and he did not have a job. The differently-abled-child studied until plus two. The third child studying in plus one.

At some times, the child quarrels with her and speaks to her. When the child saw something, the child becomes happy. The child told her about when she became happy. The child becomes Silent when the child becomes angry with anyone. When her daughter's children go to her Home, the child became very happy. The child hurts children when the child dislikes them. Nevertheless, no problems to others. The child plays and talks with siblings. Earlier, she took the child to any functions. But now she did not take the child to functions. Because the child Travels with the help of a wheelchair. For visiting the church, they seek the help of Auto rickshaws after becoming the age of 20. Then she takes all Sundays the child to the puja in chappal near kurushady near her house. On all Saturdays, the child spends his time on the beach near her house with her for refreshment. After following these routines, the child started to become happy. When taking the child outside she never felt that others are looking at her child doubtfully. The child studied for 2 years in nursery. After that, the child studied in Puthiyathura school. At that time, she takes her child to school by walking and sometimes by Auto rickshaw. When the child started to go to school the child asks her to stay in school with him. After that, the teachers understood that the child will study in school without her mother. Then she stopped staying in school and call him back at 3 o'clock. She introduces new people Who go to their house. The child forgets some relative's names. But she tries to introduce them again. After the 4<sup>th</sup> standard, the child studied in Karumkulam school, and he studied there at 7 Th standard. After spreading covid- 19 a teacher went to their house and teach her child. But He did not remember anything after studying it. She tried to teach the child by tuition. But the attempts were failed all the time. By doing these, she tried to encourage her child to get a job. She has not that much knowledge to teach the child. For not studying, scolding is prohibited by the child's teacher because the child cannot study. It's not his fault. But she scolds the child When she gets angry. The child likes to go to a special school than a normal school. Because in special school the teachers taught the children by analyzing their abilities. For example, special Schools teach differently abled children to dance, sing, etc. For elder children,

the teachers in Special school taught children job-related studies. For example, making umbrellas, pillows, Pearl materials, bracelets, earing, etc. The child's eyesight is low. Because of that, the teachers did not teach the child needle-related works. After spreading covid-19, the child is very Annoying in the house. Now 1 year passed without going to school. The tension about it can be Seen in the child's face. One day she took the child to the school and shown the HM. The child participates in painting competitions in a special school, and he achieves prizes also. The parents Must go with the child when going to competitions outside the school. The neighbours are very Loving to the child. Her anxiety is that, after her period who will take care of the child. The child is close to all family members. She is the one who helps the child to bathe and the basics of the child. When she disabled to do these the child's father can be taken care of the child.

She buys coloring books and materials for the child. She also buys toys of English letters, one two-three, etc. Now the child lost his interest in these things and tired of them. A wheelchair the child got earlier from the hospital. But now it is damaged, and it is adjusted with a rope to Use it. A wheelchair for the child is very important and she has a desire to get a wheelchair for the child. When she went outside, she does all the works for her child. The child is very lazy to drink water. The mother and father of the child equally care for the child. But the childlike his father more. The child is also very friendly with the children of the special school.

She feels difficulty when doing all the household works and caring for the child alone. The school bus goes near her house and the road has some limitations. The child knows when the school bus will come. The child is getting a scholarship and pension as a benefit from the Government. The child's sibling has a bike for 2 years. She has tension to manage time. She knows when the child's mood changes. When the child became angry, she pacifies the child. When the child fight for something, if possible, she brings it for her child. Failure of it makes Her tensed. The child asked for his mobile phone. She felt like that she has never done things lonely. When she became sad, she cries. She spends more time with her child. The child cries when he saws mother is doing all the jobs lonely. They did not feel that the child is affecting Their husband-wife relationship. She did not know how much money they spend on the child's education. She has no record of that. If she is affected by any worries, she tells her God. When her mother was alive, she told her worries to her mother. Now they are in economical difficulty comparing to earlier. They have no income as before. She also bought a loan from them Sangam. So, she is in a difficult situation.

## CASE 7

Mrs. Shaji , whose age is 46 and she studied up to SSLC. Her family is a nuclear family. She has A terraced house, and it was the house they got in the tsunami. It has been 11 years since the house was built. Until then, she lived in a rented house. Her ration card is BPL and before this, it was an APL card. They have their health insurance card. Her health insurance card had been renewed due to an accident. But other's health insurance card has not been renewed. She is a Housewife. She could not go to work because of an accident. Her husband works in a school. The monthly income of the family is 12000. The child is receiving a pension and the amount spent on the child has not been calculated. They were spending for the child and everyone. The child has minor discomfort in her body because the body swells. The child had been on medication since childhood. The child was still taking medicine. The name of the child is Telma, whose age is 22. The child has a mental and physical issue of 68 percent. The child's fingers clinging to each other, and the child was unable to memorize things. The teachers at the special school would tell her to let the child work on her own and the teachers would say that she was the one who refused to let the child work. After that, she would tell the child to clean the house and the yard with a broom. The child used to do as much as she could do. When she told the child everything, her daily routine changed. Her biggest difficulty is not telling the child when the child is in the period. She has three children. The second child is studying nursing. Seeing the hardships at home, the third child went to convent to become a sister after Plus two. A year after the desire was taken away and she returned because of ill health. The Third child was treated after coming home and she is now studying BCom in a private Institution.

The child tries to engage in talks with her. In some times the child talks lonely, and the child ignores her words. At some times the child took the phone and sit anywhere where no one disturbs the child. When a visitor goes to their home if the child knows them the child talks to Them about where is child's mother or what is she doing. The child could not talk like an ordinary child. The child started walking after the age of 4. When the child was small, she took the child to the kurushady and cry and pray for the child to walk. She sees a child's walk as a miracle. Because all are believed that the child could not walk. But she did not discard her hope. Evening time the child goes to the terrace and makes some actions on her own. When neighbours ask about it, she said that the child is speaking to an angel and they did not need to bother about it. When taking the

child to the church, she feels grief remembering about the others look on the child. When a close relative invited her to the marriage function, they tell them that the differently abled child no needs to go to the function. According to her, insulting anyone is not good. She could not leave the child alone in the house. Especially because of a girl child. The child forgets the names of relatives who visit their house. But she tries to teach the name of them. The teacher at the normal school recommended the special school for the child. Because in special school these kinds of child's get more attention. After that, she admitted the child to Thamizhnad boarding school when they are living in Thamizhnad. Then the child went to Vattappaara boarding school. After that, the child weakened so much. The child started to talk small words neatly. The child also helps her to wash the clothes. According to her, a special school is best for the child for proper caring. The childlike coloring and the child got prizes for that also. She buys coloring books for the child and tries to give the child whatever the child likes. The neighbors are very loving to the child. In urgency, she tells the neighbor to watch the child. The anxiety of her about the child is, after her who will look after the child. The child is very close to her and small children and also, she like others in the family.

She never makes the child alone in the house. Sometimes she takes the child to her sister's House. The child's mother and father care for the child equally. After school, the child tells a complaint about the school. According to her, the teachers also have limitations to taking care of the child. She did not know, whether the other children of special school helped the child to Improve the child's daily life. The childlike to travel by bike. They have no vehicles. They are facing economic difficulties now. The pension of the child is a relief to them. But she has no savings for the child. The fund which gets for the house maintenance helped to close the loan and close the exam fees of the child's sibling. The rest of the money they spend on house Maintenance. The child did not take any medicines regularly.

Sometimes she feels difficult to manage time. Clean drinking water is less in their area. It affects their day-to-day life. She spends more time with the child. It is difficult to stop the child's crying when the child started once. The child also becomes sad without any reason. She did not feel like that because of the child she did not able to do new things in her life. When The child's father goes to work far away from the house, he committed a relationship with another Muslim girl. After affecting by the disease, the child's father came back home and recovered. Now they are living

happily. Sometimes she feels like that, she did not do works Alone. She spends more time with her child. The situation-based cost of the study material change. Bus fees and tour fees are the main cost of it. When she becomes sad, she talks about It to her children. They are now in an economic crisis.

## **THEMATIC ANALYSIS OF THE CASE STUDY**

### **PERSONAL PROFILE OF THE RESPONDENCE**

Out of the seven parents', five of them are the age of 40 and 40 above. The other one was above 50 and one was above 60 years old. Two of them completed their SSLC and the other five Studied above 6<sup>th</sup> standard. This reveals the earlier poor economic condition of their family. But all have education skills and if they got a chance in the past, now their life would have changed. One of the parents is a widow. She has no partner support for taking care of the Differently abled child. But she has family support to caring the child. Other parents are (six) Married and they have two to three children with one differently abled child. All the families Have only one differently abled child. The siblings of the differently abled child also facing Stress in life because of their family situation. Out of the seven parents, six were living in a nuclear family and one was living in a joint family in her mother's house. She is a single parent Also. It can be observed that more families are going with the modern world method (nuclear Family).

### **SOCIO- ECONOMIC PROFILE OF THE RESPONDENT**

Out of the seven parents, six of them are Christian and one was Hindu. Seven of them have a Terraced house. But one of them lives in a rented house because of the economic crisis. One was got the house after the tsunami crisis, from the government. Before that, they live in a rented house because of economic problems. They all have health insurance cards. One of them has a ration card of APL and others have BPL cards. This shows that most of the parents live in a middle-class family. Our seven of the respondents are female mothers and they are a housewife. One of them is a retired Anganwadi Helper and her husband did not have a job. Her Family's expenditure is done through her income. Other respondents' husbands work as tailor, Fishermen, and schoolteachers. Some of them, especially fishermen get their income according to their situation. So, they do not know the actual monthly income of their family. However, the families of the respondents get 400 to 12000 rupees per month. From it, five families get Above 1000 rupees, and one got 375 and

where gets the highest income as 12000 rupees. This shows that all the respondent's families have different economic capabilities. They did not know accurately how much money they spend on their children. Because they need to spend the money according to differently-abled child's daily needs. Four of the differently abled children were not regularly taking medicines, because of the side effects of the medicine. Three children had been on medication since childhood and the child is still taking the medicine. Other parents gave medicines to the child when the child is affected by any other health issues. We can analyze that more medicine intaking is not good for the health. It leads to other health Issues. But in some cases, regular medication is needed.

### **CHILD DETAILS**

Five children are above 19 and two are above 25. All the parent's Differently abled child has both physical and mental issues. Five of the children have a disability of above 59 percent and one was 80 percent and one's disability is 95 percent. The child, which has a 95 percent disability cannot walk and her neck is not fixed. The child cannot stand well and the child is always sitting in a chair. Other children also have difficulties because Of health issues. But not much as this child. All the differently-abled children need help to do their daily life activities. For example, bathing, brushing teeth, brooming, cleaning the house, eating food, doing household Jobs and doing their basics, etc. But one child's condition is very difficult. The child could not do anything, because the child cannot move from the wheelchair and the child's neck is not fixed properly. After going to the special school, the child started becoming happy because of Seeing other children. But the child can do anything on her own.

Four of each parent have three children in their family. We can see, in one family the parent Has three daughters. Seeing the hardship at home, the third child went to Convent to become a Sister after completing her plus two. A year after the desire was taken away and the third child returned to home because of ill health. The other two respondents have two children and one only has a differently-abled child. The parents most of the children are studying. Only some Are got the job. We can analyse that, after getting a job the parent's economic imbalance will be changed.

## **SOCIALIZATION**

All the parent's child tries to interact with them differently. One of the parent's children was born speechless. So, the child tries to interact with the parent by waving his hand and making other sounds. One of the parent's child's conditions is very difficult. The child could not speak or do actions. But the child could understand what others are saying. The child's mood was only understood by crying and laughing. Through different methods the parents able to understand their child more. So, all differently abled child can express their feelings to their close ones freely. All the differently abled children only interact with known persons openly. Responding to unknowns is difficult for them. Out of the seven parents, two were experienced the abandons of the child by their relatives because of the child's condition. But now day's society is also considering these kinds of children. So, they did not identify their child as separate from mainstream society. They also possess a role in society. We can only saw rarely, these kinds of children holding back by others. Most of the differently abled children could not remember others in a long term. The parents make efforts to introduce the relatives who go to their house, to promote child's mingling behaviour.

The neighbours of the parents are loving and caring to the children. All the parents have anxieties about the future of their differently abled children. Worry is that who will take care of the child after their time. Some of them leave it to God, as the child's life will go on according to God's desire. But now they are satisfied with their life with the help of relatives and the Government. Mostly, the differently abled child is very close to their mothers. But according to them, the child is close to all family members.

## **SPECIAL SCHOOL**

The differently-abled children are studied in other schools before going to Mother Theresa Day Care Centre except one. For the parents, Mother Theresa Day Care Centre Became their last hope for the children. Other differently abled children face mental and physical difficulties from other schools. Like torturing, weakening of health, etc. most of the parents enrolled their children in Mother Theresa special school, because of the recommendation of their known persons or relatives. After analysis about the special school, they enrolled their children in it. After going to Mother Theresa special school, all the children have improved their skills. Because special school is good in teaching, cleaning, caring, food, etc. The special school Teaches the students by dividing



them into sections according to the child's ability. It helps to Teach the children easily and effectively. The Mother Theresa special school also provides physiotherapy for differently abled children. After going through physiotherapy, the changes Seemed in children. According to the parents, for proper caring of the child, special school is better than normal school. But at the same time, by studying in a special school, the child was lost the opportunity to mingle with the normal children. Most of them started studying in a normal school. But situations of them bring their child to a special school. The special school has competitions in sports, organ, painting, colouring, drawing, etc. Seven, out of five children are participated in different competitions and achieved several prizes. The special school gave opportunities to the child to improve their skills and the teachers are trying to help the children with it.

### **SUPPORTING SYSTEM**

Most of the parents of the differently abled child have bought books, coloured pencils, sketches, colouring books, English letters, toys, etc for their child. One parent's child could not have the ability to try these things because of the child's problem in the nerve in the brain. Because of it, the child could not do anything. One parent bought a bicycle for her child. But The child cannot ride on it. The special school also has toys to play with for the children. Teachers went to some parent's houses from different institutions to teach the children in the Covid-19 period. We can understand that to give social support to the differently abled child, The parents and teachers are working equally. In the absence of the parents, other family members are taken care of the differently-abled child. Because the children also a part of the family. The parents both take care of the child equally. But the mother of the child gives more care to the child when the father goes to work. One of the parents is a widow. She takes care of the child with the help of other family members.

After going to a special school, the children learn to look after their affairs. But there has not been much improvement in the study. Because the children have some limitations to remember the lessons. After going to a special school, the children started to become happy and try to Interact with people. We cannot say that mingling with the children of the special school Improved the child's skills. The students of the special school also have some difficulties. It cannot link with their child's development. But the children have good friends with each other. The children are very happy to go to a special school. But after the spreading of covid-19, they Are prohibited from

going to school. This negatively impacted the improvement of the children. Most of them did not have the facility to attend the online class.

Each parent faces different barriers to give social and material support to their child. In transportation, infrastructure, caring, etc. according to them, there are more disabled children in special schools comparing with their children. The condition of differently abled child's In shore areas is unbearable and all of the children are in a state where their arms are crooked, Their faces are crooked, and unable to stand up. The differently abled child was gone through different medical treatment. Some are affected by side-effects of the medicines. The special School has a school bus. lack of wheelchair, two of the respondent's children face difficulty to Travel in bus and face difficulty in doing other things also. The children need a wheelchair for proper caring of them. The economic conditions of the parents are low to look after the children. After the arrival of covid-19, the situation of the parent's economic condition was worsened. The children need anyone's support to do their daily life activities.

The government's provision of a pension to differently-abled children is undoubtedly a step towards offering economic support to their families. However, as reported by parents, this financial assistance falls short of fulfilling the comprehensive needs of the household. While the pension might alleviate certain economic burdens, it does not encompass all the expenses associated with raising a child with disabilities. This points to the complex nature of the challenges faced by these families, extending beyond financial considerations. In terms of education, the limited scholarship provided by government schools, which amounts to 1100 rupees, reflects a partial attempt to support differently-abled children's educational endeavors. Additionally, the occasional assistance from Anganwadi serves as a temporary relief, yet it does not provide consistent support throughout the year. The situation is distinctive for private institutions like the Mother Teresa special school. While they are unable to offer scholarships, they do extend fees concessions to children based on their families' economic conditions. This showcases a commendable effort by the school to ensure that education remains accessible to these children. Transportation emerges as a concern for most families, with only one respondent having access to a personal vehicle. The reliance on autorickshaws for travel underscores the need for more accessible and cost-effective transport options, considering the unique needs of differently-abled children. Although these children might

express a preference for two-wheelers, it's important to prioritize their health and safety over desires.

Medication patterns among differently-abled children vary, as only one child adheres to a regular medication routine. This might be attributed to various factors, including the nature of the disability and the treatment plan prescribed. Some families find themselves unable to afford visits to higher-quality hospitals, highlighting disparities in healthcare access. Moreover, concerns regarding medication side effects lead some parents to discontinue regular medication. This underlines the delicate balance between treatment and potential adverse effects on the child's well-being.

In summary, the accounts provided by respondents reflect the intricate and multifaceted nature of raising differently-abled children. While the government's pension and educational support offer some relief, they don't fully address the broader range of needs these families encounter. Transportation, healthcare access, medication management, and the complexities of treatment are integral components that shape the experiences of parents and their children with disabilities. These findings highlight the necessity of a holistic approach to support these families, encompassing financial, educational, healthcare, and social dimensions.

## **CHALLENGES FACED BY PARENTS**

Among the seven respondents, managing time emerges as a common challenge for four of them. Balancing household chores and caring for their children with disabilities presents a considerable hurdle. This struggle is compounded by external factors such as the lack of clean drinking water, which further complicates their daily routines. Three respondents, however, exhibit a different attitude, believing that they don't need separate time for their child's care. For families with girl children, giving extra attention to their care is vital, and leaving them unattended is not an option.

The parents are attuned to their differently-abled children's emotions and behaviors. They can identify changes in mood, anger, sadness, and happiness and respond accordingly. Communication is diverse, encompassing talking, crying, smiling, and expressing various emotions. Some children exhibit unexplained sadness, emphasizing the complexity of their emotional experiences.

Participation in functions and events varies, with only two parents taking their children to functions based on distance and familiarity of relatives. Recognizing the importance of their children's happiness and social interaction, parents should strive to create opportunities for their children to enjoy life beyond the confines of their home.

The parents unanimously view their differently-abled children as unique gifts from God. They harbor a positive perspective, considering the child's uniqueness rather than seeing it as a hindrance. Family support is pivotal in managing daily tasks, reinforcing the notion that collective effort within the family helps alleviate the challenges.

The relationships between parents and their spouses remain unaffected by their differently-abled children. Fathers actively participate in caring for their children, and the parents' unity in managing challenges contributes to the family's resilience.

Financially, parents prioritize their children's care, with most not quantifying the exact amount spent. Expenditure is directed towards medicines, school, transportation, and other essential needs. In times of distress, parents seek solace through sharing their worries with neighbors, relatives, children, or a higher power, finding relief in sharing their burdens.

The impact of COVID-19 is evident in all families, disrupting routines, and causing economic difficulties. The closure of special schools during lockdowns affects the children's emotional well-being. Although some parents faced COVID-19 and recovered, the pandemic's economic repercussions linger, forcing some families to resort to loans for financial support.

In summary, the experiences of these families underscore the multifaceted challenges and triumphs of raising differently-abled children. Time management, emotional understanding, social inclusion, positive perspectives, and adaptive coping strategies are woven into their narratives, revealing the intricate tapestry of their lives. The ongoing impact of COVID-19 accentuates the resilience and adaptability of these families in the face of adversity.

## CHAPTER V

### FINDINGS SUGGESTIONS AND CONCLUSION

The conclusions drawn from the analysis of the respondents' answers and the categorization of themes provide valuable insights into the lives of parents of differently-abled children. The research identifies seven main themes that encapsulate the cases: Personal profile of the respondents, Socio-economic profile of the respondents, Child details, Socialization, Special school, supporting system, and Challenges faced by parents. Each of these themes has been thoroughly analyzed and explained in the preceding chapters.

The initial assumption of the researcher, that most respondents would be above the age of forty, held true. All respondents are literate, with two of them completing their SSLC education due to earlier economic constraints. All are married except for one widow. The majority (six of them) belong to nuclear families, while one respondent is from a joint family. This study unveils that the siblings of differently-abled children also experience stress due to their family situations.

An important finding is the impact of medication intake on differently-abled children's health. While regular medication is necessary in some cases, it's observed that excessive intake can lead to adverse side effects. Six of the respondents identify as Christians, and most have health insurance cards to assist them during difficult economic times and medical treatments. Their economic status generally falls within the middle-class range.

The assumption regarding the age of differently-abled children (most between 14 to 45) is confirmed based on enrollment at the Mother Theresa Day Care Centre. Children admitted to the Mother Theresa special school typically have over 50% disability. Despite the challenges, the special school's efforts yield positive results, with students showing improvements in daily activities and happiness. Siblings of these children are mostly students, with a few employed.

Communication with differently-abled children is diverse, utilizing various methods. Respondents note that their children can express feelings freely, albeit with difficulties responding to unknown situations. Anxieties about their children's future care persist among parents, leaving questions about who will look after them once the parents are no longer able.

The distinction between Mother Theresa Day Care Centre and other schools becomes evident. The special school offers improved teaching, cleanliness, care, accommodation, and even physiotherapy. However, it's noted that attending a special school limits interactions with typically developing children.

Social support is a shared effort between parents and teachers, with parents taking equal care of their children. However, it's observed that mingling with children from special schools might not significantly enhance skills due to the shared difficulties. The pandemic's prohibition on attending school has negatively affected differently-abled children's progress, especially as online classes are not always accessible.

The provision of a government pension is noted as an economic support for these families, although it only partially covers the child's care. Time management proves challenging for many parents, particularly due to the dual responsibility of household tasks and child care. Socialization for girl children requires additional attention, and children express their emotions through various means. Parents acknowledge the need to attend functions for their children's happiness, emphasizing that four walls cannot suffice for their growth.

The economic challenges worsened due to the pandemic, leading some families to take loans for support. The conclusions encapsulate the multifaceted nature of the challenges and triumphs experienced by parents of differently-abled children, offering a comprehensive understanding of their lives.

## **SUGGESTIONS**

The provided points outline important recommendations to improve the support and well-being of physically and mentally differently abled children, as well as their families. These suggestions address various aspects ranging from education to infrastructure and emotional support. Here's a breakdown of each recommendation:

### **Promote Intensive Skill Development Activities:**

Encourage skill development programs tailored to the abilities and interests of differently-abled children.

These programs should focus on enhancing their skills, independence, and potential for future employment.

**Provide Special Grants to Institutions:**

Allocate special grants from the government to institutions catering to differently-abled children.

These grants can help enhance resources, facilities, and overall quality of education and care.

**Establish Adequate Institutions with Trained Teachers:**

Establish specialized institutions in each district with well-trained teachers and staff.

These institutions should provide comprehensive education, therapy, and care to cater to the unique needs of differently-abled children.

**Adequate Infrastructure for Families:**

Ensure that families of differently-abled children have access to adequate infrastructure facilities.

This could include accessible public spaces, transportation, and housing accommodations.

**Provide Counselling to Parents and Family Members:**

Offer comprehensive counseling and emotional support to parents and family members.

Counseling can help families cope with challenges, understand their child's needs, and develop effective strategies for care and inclusion.

**Special Allowances for Parents:**

Provide financial allowances to parents of physically and mentally disabled children.

These allowances can help cover expenses related to education, healthcare, therapy, and other essential needs.

**Adequate Infrastructure for Institutions and Individuals:**

Ensure that both institutions and individuals with disabilities have access to suitable infrastructure.

This encompasses accessible buildings, transportation, and facilities that promote inclusion and independence.

These recommendations underscore the importance of comprehensive support systems for differently-abled children and their families. They address the need for tailored education, financial assistance, emotional well-being, and accessible environments. Implementing these suggestions would contribute to fostering a more inclusive society that values and supports the unique abilities of every individual.

## **CONCLUSION**

The provided text captures the essence of the study's findings and conclusions regarding the challenges faced by parents and guardians caring for mentally and physically differently-abled children and adolescents. It also underscores the crucial role of families, institutions, and support systems in nurturing these individuals. The study delves into various areas, including the parent-child relationship, education and skill development, socialization, and safeguarding the rights of differently-abled children.

The study recognizes parents and guardians as pivotal caregivers for mentally and physically differently-abled children and adolescents. Their role is essential in providing care, support, and creating an enabling environment for these individuals.

The study highlights the importance of understanding the challenges faced by these caregivers. Identifying and acknowledging these challenges is the first step toward improving the support provided to them.

The study emphasizes the significance of providing appropriate care and support for differently-abled children and adolescents at home and during outpatient hospital visits to address their mental health needs effectively.

The study's significance lies in its contribution to a deeper understanding of the challenges inherent in caring for mentally ill children. This understanding is crucial for devising effective ways to enhance support for caregivers.

The study acknowledges the varying coping patterns of parents living with differently-abled children. Some parents find it challenging to cope, while others adapt more easily. Stress-related problems can impact daily work performance and family dynamics.



Financial burden emerges as a significant challenge for parents, given the higher expenses associated with the education and healthcare of differently-abled children. The costs of education, medication, and consultations contribute to these financial strains.

The study underscores the importance of raising awareness among parents about government schemes and policies aimed at providing financial assistance and support. Awareness can help alleviate the burden on parents and improve opportunities for children.

The study highlights the importance of institutions like Mother Theresa Day Care Centre, which provide skill development programs, therapies, and care for differently-abled children. Such institutions contribute to improving the condition and productivity of these children in society.

The study concludes that special schools play a significant role in enhancing the well-being and capabilities of differently-abled children. These schools provide a conducive environment for growth, skill development, and socialization.

The study ultimately calls for improvements in the condition of differently-abled children and emphasizes that they have the potential to contribute positively to society. Special schools and support systems can play a vital role in empowering these individuals to lead fulfilling lives.

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## **APPENDIX**

### **INTERVIEW GUIDE LIVED NARRATIVES OF PARENTS OF CHILDREN WITH DISABILITIES**

#### **Personal Details**

- Name
  - Age
  - Education qualification
  - Family type (single parent/ separated/ dysfunctional family/ step parents/ nuclear/ Joint).

#### **Socio-Economic Details**

- Religion
- Caste
- Housing status
- Ration card type
- Health insurance card
- Occupation of the parents.
- Monthly income of parents
- Monthly expenditure for your child

#### **Child Details**

- Age
- Health issue
- Percentage of disability
- How many children? (male/ female)
- Education qualification.

#### **Socialization**

- How does your child try to interact with you? Are this interaction leads you to a better Understanding of your child?
- Does your child try to interact with other people?
- Does your child have any difficulty in socializing?
- Was there any bad experience when your child tries to interact with society?

- What were the efforts that you had taken to socialize your child?
- Have you enrolled your child in any school?
- The reason which you enrolled your child in a special school?
- Do you think that the special school has any role to socialize the child?
- Which school is best for the proper care for your child (normal school or special school)?
- Have you been able to establish a good relationship with the child's special school
- How does it help you?
- Does the special school promote any skill development activities/ socialization?
- How is the neighbour's interaction with your child?
- What are the anxieties about your child in socializing? (e.g.: marriage, family) To whom the child is close?

### **Supporting System**

- What are the things you have done for your child to give social support? What are you going to do?
- What are the material supports that you have given to your child? How it helps the growth of your child?
- Who is the caretaker of your child in your absence?
- Do you get good support from your partner to taking care of the child?
- Has the special school given the needed support for your child?
- Were there changes after going to a special school? What are the changes that you identified?
- Does the interaction with the other children in special school help the child's daily activity and involvement in society?
- What are the obstacles that affect the material & social support of your child? (e.g.: Transportation, caring, infrastructure). Which is the most leading obstacle?
- Have you got any benefits from the government or a special school for your child? If No, is your revenue is enough for taking care of the child?
- Do you have any vehicles in your home?
- Does your child need any medical care? If yes, do you access to give medical care regularly?

### **Challenges Faced by Parents**

- Do you face difficulties in managing your time wisely?
- Does your child share his/her feelings with you?
- Do you take the child out for public gatherings or social get together? If yes, what was The opinion of others?
- Since, having a child with special needs, did you ever feel that you are unable to do New and different things?
- Did you ever have a feeling that you cannot handle things alone?
- Have you ever felt that you are giving up more of your life for your child's needs than You ever expected?
- Does having a child who needs special attention affect your relationship with your Spouse?
- How much do you spend on education for your child?
- Do you ever share your thought/feelings with others? If yes, with whom?
- How do you take your family situation as of now?

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