

# Understanding the Problems and Challenges of Caregivers of Disabled Children: A Study

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**Abstract:** Disability among children is one of the burning problems in India and the world. Many children have suffered from disabilities. The disability of children can affect a family's finance, employment and health in the shape of direct and indirect costs. Direct cost includes medical care, medicines, therapies and indirect cost includes expenses on transportation, education, caregiving etc. According to the 2011 census there are 2.68 Cr persons are disabled population are living in India which is 2.21% of the total population. The present study is conducted with the caregivers of the disabled children of Visakhapatnam. The study found that (80%) of the caregivers are between 26 and 60 years age group. The study found that an average of 85.2% of caregivers surveyed had no formal education. The study found that the majority of the respondents (40%) not working and the remaining are working only do agriculture or daily wage. The majority (75%) of the respondents have reported that they don't get time for themselves and more than 55% have issues of anxiety and somatic problems. The study found that the majority (80%) of the respondents have strained relationships due to the impact of their caregiving. The majority of the respondents worry about their livelihood security. The study suggested that there is a separate intervention to promote the quality of life of children with disability

**Keywords:** child health, disability, caregivers, psychosocial support.

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## 1. INTRODUCTION

Disability is defined as the inability to perform an action that is deemed normal for a human being or the difficulty a person has performing tasks that others take for granted (World Health Organization, 1996). There are many types of disabilities, such as affect a person i.e. vision, movement, thinking, remembering, learning, communicating, hearing, mental health and social relationships. According to the World Health Organization, disability has three dimensions:

1. Impairment in a person's body structure or function, or mental functioning; examples of impairments include loss of a limb, loss of vision or memory loss.
2. Activity limitations, such as difficulty seeing, hearing, walking, or problem-solving.
3. Participation restrictions in normal daily activities, such as working, engaging in social and recreational activities, and obtaining health care and preventive services.

### Statistics of Disability

Disabled children can affect families' finance, employment and health in the shape of direct and indirect costs. Direct cost includes medical care like medicines and therapies and indirect cost includes expenses on transportation, education, caregiving etc. (Staline & Allin, 2012).

Nearly 240 million children in the world today have some form of disability. This estimate is higher than previous figures and is based on a more meaningful and inclusive understanding of disability, which considers several domains of functioning, including those related to psychosocial well-being (UNICEF, 2022). In India out of the 121 Cr population, 2.68 Cr persons are disabled which is 2.21% of the total population. Among the disabled population, 56% (1.5 Cr) are males and 44% (1.18 Cr.) are females. In the total population, the male and female populations are 51% and 49% respectively. The majority (69%) of the disabled population resided in rural areas (1.86 Cr disabled persons in rural areas and 0.81 Cr in urban areas). In the case of the total population also, 69% are from rural areas while the remaining 31% resided in urban areas (enabled. in, 2023). As per the 2011 Census, the total disabled population is 12,44,402, registering a growth of 21.84 per cent during the decade (Enabled. in, 2023).

### Understanding Disabilities

National Trust disabilities can also be termed Developmental Disabilities. They are caused due to insults in the brain and central nervous system. These are not contagious or Progressive. They cannot be cured by drugs or surgery. Early detection and training are vital. This is done using the services of Physio-Occupational and Speech Therapists, Community Based Rehabilitation Workers and Special Educators. The cause could be due to several environmental factors which deprive the brain of oxygen before, during or after birth.

**Cerebral Palsy:** Traditionally described as "an intelligent mind caught in a disobedient body", is typified by motor dysfunction. Gross motor (sitting, sewing, painting etc.) and speech are generally affected.

**Mental Retardation:** The cognitive area of the brain is affected, leading to slow learning and responses. The child will take a long time to understand and may need to be explained in simpler terms, one thing at a time.

**Multiple Disabilities:** "Multiple Disabilities" means a combination of two or more disabilities like Deaf blind, Cerebral Palsy with Mental Retardation, or Mental Retardation with Visual Impairment. Given appropriate training, people with the above disabilities can work productively and contribute positively to their families and community (Pavanaran Kosuru, 2018)

## 2. REVIEW OF LITERATURE

**Leonard et al. (1992)** study reported that parents with disabled children lost their jobs and had to devote more time to their children's care. Care for seriously disabled children involves both medical and non-medical activities. Day-care facilities may also refuse these children due to medical difficulties, or they may be prohibitively expensive. As a result of these factors, moms may lose their jobs or have their working hours cut.

**Doe (1995)** discovered that having handicapped parents has a significant economic impact. Because of their illness, these parents frequently pay additional fees for transportation, prescriptions, or home adaptations. They also require more income for the upkeep of their children. Adults can use paratransit systems or other alternatives for transportation, however many of these systems do not allow children of disabled parents to accompany them to school or the doctor's office.

**Kandamuthan and Kandamuthan (2004)** conducted research in South India to evaluate the impact of disability on family economics and spending patterns. The study included approximately 300 homes with typical children and 300 households with atypical children. According to the data, families with disabled children spent an average of 254 dollars per year, compared to a family with regular children who spent 181 dollars per year. Furthermore, 90 per cent were refused access to healthcare and basic education, and 21 per cent of women with disabled children were unemployed, compared to 12 per cent of mothers with children with normal development.

### Statement of the problem

Disability among children is one of the burning problems in India and the world. The children who have disability have suffered a lot. The lives of children with disabilities can be surrounded by stigma, discrimination, cultural prejudices, ill-perceptions and shocking invisibility. In addition, children with disabilities are at dramatically heightened risk of violence, neglect, abuse and exploitation (United Nations, 2022). The children's disability creates a lot of impact on the socio-economic and psychological conditions of the family. Very fewer studies have been conducted on this phenomenon in Andhra Pradesh and India. In this regard, the present study is conducted to understand the impact of children's disabilities on family members.

**Objectives of the study**

1. To Study the socio-economic conditions of caregivers of the disabled children
2. To Study the problem faced by the caregivers of disabled children
3. To Study the mental stress levels of the caregivers of disabled children
4. To provide the appropriate suggestions to promote the quality relationship between caregivers and children

**Study area**

The study was conducted in Visakhapatnam. The study interacted with the children who came for treatment in government hospitals from different parts of Visakhapatnam. The main mission of these hospitals is to provide specialist Orthopaedic & paediatric services and to promote health care. They provide diagnostic services to the inpatients and as well as outpatients, physiotherapy services, and speech therapy are also provided. Surgical treatment of deformity correction of cerebral palsy, club foot and other orthopaedic conditions.

**3. METHODOLOGY**

A descriptive research design has been selected research for this study. Both qualitative and quantitative has been collected from the respondents by conducting interviews. The study adopted a purposive sampling method and selected 40 care givers of children with disability. The study conducted with the care givers of the disabled children. The "A caregiver is a unpaid individual (male/female) involved in assisting others with activities of daily living and/or medical tasks of children with disability. The quantitative data relating to the income and expenses of the family have been collected. Qualitative data relating to the emotional burden stress of the members of the family. The data were analysed through MS-Excel 2010 version.

**4. RESULTS AND FINDINGS**

1. The data in the study revealed that the majority (80%) of the caregivers are between 26 and 60 years age group.
2. The study found that an average of 65.2% of caregivers surveyed had no formal education.
3. The study found that the majority of the respondents (40%) not working and the remaining are working only do agriculture or daily wages as per the baseline study shows.
4. The majority (65%) of the respondents are from rural areas. They came from rural areas and stayed in the hospital for the treatment of their children
5. The majority (75%) of the respondents have reported that they don't get time for themselves and more than 55% have issues of anxiety and somatic problems.
6. The study found that the majority (80%) of the respondents have strained relationships due to the impact of their caregiving. The majority of the respondents worry about their livelihood security. The study is inline with the study of Dalia Zahaika (2021) who reported that the majority (88.5%) of the caregivers felt physically exhausted, about (75.4%) had decreased living standards, and (86.2%) indicated that caregiving is taking their strength.
7. The majority of the caregivers have accepted their children's status and spend the time to provide care, support and treatment to them. Parents must accept the fact that children with disability have functionally different brains from those of other children. While children with disability can still learn what is acceptable and what is not, the disorder does make them more prone to impulsive behaviour.
8. It is found that only 25% of disabled children have good pronunciation and the remaining children have speech problems
9. The study found that the majority (62%) of the respondents have spent more money on their children and they borrowed money from money lenders and the relatives
10. The study found that the majority (55%) of the respondents have faced discrimination from their relatives and neighbours due to their children's disability

11. The study found that Families caring for children with disabilities face particular challenges and demands compared to those caring for children without disabilities

12. The study is in line with the study of Zabidi, A. S., et al. (2023) who reported that parent-child relationship quality in intellectual disability has been associated with child mental health. Shared time in leisure activities was significantly associated with parent-child closeness and conflict. Spending time in joint leisure activities may be a path for improving closeness and reducing conflict in parent-child relationships.

13. The study is in line with the study of Vanegas, S. B., (2023) who reported that many children and families in racially/ethnically and socioeconomically diverse communities face pervasive, systemic issues that contribute to significant inequities in access to and receipt of services. Researchers and providers have an ethical responsibility to acknowledge and address the needs of children and families, especially when working with underserved communities. This includes providing referrals and resources to services and supports in the community or even incorporating case management within the scope of the project

### Suggestions

1. It is recommended that the problem of educating disabled children needs much research following qualitative and quantitative paradigms. The researchers should find strategies to teach disabled children. It will reduce the impact on the family members

2. Parents and caregivers will need to adapt their ways of interacting with the child. This includes speech, gestures, emotional language and the physical environment. For a child with a disability, consistency is vital. By using a supportive and structured approach, challenging behaviours can be limited and the child can flourish.

3. The parents and caregivers should follow the following activities with disabled children i.e. Keep it interesting, Think out loud, Keep distractions to a minimum, Try bedtime message, Be creative and cooperative, Identify the child's strengths, Don't blame yourself, Don't blame other family members, Give praise and encouragement, Introduce wait time, Do not get overwhelmed and Explain rather than command. They should have to contact doctors occasionally to get the appropriate treatment

4. Encourage them to talk about their feelings. Children with disabilities often experience feelings of social isolation from their peers, and social distancing policies related to COVID-19 may amplify these feelings. Give your child opportunities to discuss these feelings and brainstorm ways for your child to interact with others through texting, phone calls, video chatting and other virtual platforms.

5. Government organisations and non-governmental Organisations should work for the development of orphan and disabled children by introducing the focused interventions. Government has to accord the highest priority in responding to the urgent needs of these children with appropriate and immediate actions on the ground (Abraham Mutluri, 2016).

6. Every child with a disability has strengths. These may be in doing artwork, in their personality, or in their motor skills. Every child has strength. It's more important for us to focus on what children can do with their abilities, rather than their disability. We can use children's abilities to assist the areas that they have the most challenges with.

7. There is a lot of scope for the practice of social work profession with these children. Social workers work as social case workers, social group workers, community organizers, social activists, social welfare administrators, social researchers, counsellors, communicators, and educators etc. (Abraham Mutluri, 2021)

8. The study understood that there are 21 types of disabilities recognised by the government. It is the responsibility of every citizen to care about their needs

## 5. CONCLUSION

The parents of disabled children spent time, money, effort to change their children into the normal children. There are millions of caregivers in Andhra Pradesh and in the whole country who are always engaged in giving services to the disabled, sick, old age or people with any kind of ailment. One has to re-think how their services can be recognized, how their rights can also be ensured so that they continue to give their caregiving responsibilities, can address their own health and emotional needs, find ways to support their families, and all should come together to a platform to advocate for their entitlements. The role of caregivers must not only be identified, but also be recognized and their efforts supported with

resources, and organizing them to play the role of advocacy force to meet their needs is also vital. If caregivers of children with disabilities are empowered to effectively address the challenges they face, the care they provide to their recipients will improve and then children's physical, emotional, social and functional well-being will be enhanced. Empowering caregivers will be of benefit to children who are disabled as well as the caregivers. The physical and psychological distress caregivers experience as a direct result of their caregiving duties is drastically reduced when caregivers receive adequate support (Alzheimer's Society of York, 2018). A person with illness impacts not only her/his life but also affects the functioning at the family level and their contribution to the community. Thus, caregivers act as a bridge between the ill/disabled person and the community/outside world by facing the brunt of caring.

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