

**“DISABLED CHILDREN AND THEIR IMPACT ON FAMILY”**  
**A SOCIOLOGICAL STUDY WITH SPECIAL REFERENCE TO DISTRICT**  
**KULGAM (JAMMU AND KASHMIR)**

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## **Abstract**

The purpose of this study is to understand preferably the differential impact of disabled children on their families. Since all families go through ups and downs, and those ups and downs may alter the family structure in various forms like financial and development problems may arise, also their children may be affected as they grow and mature. Families may be exposed to many stress factors such as: a divorce, a family dispute, a death, a child with disabilities etc. The aim of this article is to focus mainly on the impact of the disabled children on the socio economic and other conditions of their families. The sample size that we have taken is 200 and it has been randomly chosen among different villages to provide true representation of the population. The sample units are drawn at random without showing any regard to the characteristics of the population units. To get information from the study, interview schedules and self-developed questionnaire were used. The data obtained was compiled and analyzed using simple statistics. The present study also highlights the governmental and societal response towards disabled children.

**Key words:** Disabled children, impact, family.

## **Introduction**

*“Half the world doesn’t know how the other half lives”*

In the battle for existence, there are people who are fazed by the slings and arrows of brazen fortune and vicissitudes of destiny. Disability represents a perfect example of this. The survival of



fittest became the norm and might is right has become the rule of the world. However, accepted formula for deformed and disabled person is a serious question that needs to be addressed very deeply. The disabled means the one who are incompetent and unequipped to the various multidimensional demands of life. They are born and brought up in the society and made to suffer for no fault. In fact, they are made the victims of circumstances, thereby destroying their spirit and motivation. Hence to find a proper place for them in the society, it is a matter of great concern for most of the social workers, administrators and policy makers.

Since Family plays an important role in the life and upbringing of children, as it is the first basic unit to which the child comes in contact with. According to ecological model Urie Brofenbenner (Papilla and Odds 1995), development of child takes place through interactions of micro (immediate family), meso (school, relatives and friends), exo (related meso systems) and macro systems (related macro systems).

The words 'handicapped', 'disabled', 'differently abled', 'retarded' have various meanings and carry the potential for undermining stereotypes, discrimination and abuse. Disability may relate to body or mind. Also disability can be of a short term or a long term nature. Some disability may be of permanent nature.

The most acceptable and dynamic definition of disability is provided in the United Nations Convention on Rights of Persons with Disabilities (UNCRPD) which states that, "Persons with disabilities include those who have long term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others."<sup>(1)</sup> Persons with disabilities frequently live in catastrophic conditions, facing barriers that prevent their integration and meaningful participation in mainstream society. Their basic human rights to freedom of movement, access to education and health care are often ignored. Because they suffer the additive difficulties of their disability, marginalization and invisibility, their health, especially their mental health may deteriorate even further.

Research shows that families caring for children with disabilities experience higher levels of family stress, abbreviated employment opportunities and diminished rates of general well-being than comparative families. Specifically, these stressors have a negative impact on the family's economic and emotional well-being. Families caring for children with disabilities face fastidious challenges



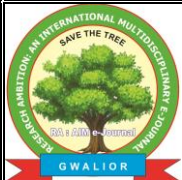
compared to those caring for children without disabilities. Challenges include demands on time, constrained earning potential, increased financial expenditures related to health care, employment constraints and emotional stress. The disabled children are deprived of all opportunities for social and economic development. Basic facilities like health, education and employment are denied to them in all the spheres of life. In spite of several international and national pronouncements, the rights of the disabled have remained on paper. Additionally, time constraints limit the opportunities for parental-social interaction and advanced education. The purpose of this research is to shed light on the family impact of caring for children with disabilities. Using a mixed method research approach we use survey, health care claims data and focus groups to describe family impact.<sup>(2)</sup>

## Review of literature

**Gupta et. al. (2012):** studied the parenting stress and its determinants among parents of children with disabling conditions in India. Female sex of the child was associated with higher stress related to failure of the child to meet parent's expectations and to satisfy the parents in their parenting role. Parents engaged in more lucrative and prestigious occupations had more stress than parents engaged in less prestigious and lucrative occupations irrespective of their income. Many parents reported receiving little support from their extended families in taking care of their child.<sup>(3)</sup>

**Ganie M. Y. and Bhat S.A.(2012):** The study was conducted to check up the mental health and academic achievement of physical challenged and physical normal students in district Srinagar (Jammu & Kashmir, India). The sample for the study consisted of Hundred (100) secondary school students (50 physically Challenged and 50 physically Normal). The investigator used Alpana Sen Gupta's Mental Health Battery to study the mental health of sample subjects. The Academic achievements of the students were obtained from the official records of their respective schools. The data collected was subjected to various statistical treatments like mean, S.D. and t-test. After analyzing the data it has been found that physically normal students possessed better mental health and academic achievement than the physically challenged students.<sup>(4)</sup>

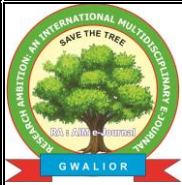
**Yadav A. M et.al (2013):** The current study revealed that there was significant difference between dysfunctional attitudes among parents having children with intellectual disability and without intellectual disability. The study was reported that dysfunctional parental attitudes that contributes to



school learning and behavior disorders. There was no significant difference between dysfunctional attitude among mothers having children with intellectual disability and without intellectual disability. A study reported the same results conducted by Lina shah, Karachi (2003), they found that mother dysfunctional attitudes and depressive symptoms of adult children are positive correlation between mother dysfunctional attitudes should more positive symptoms of adult son's compared to adult daughter's of furthermore it was revealed that the correlation between mother's dysfunctional attitudes and depressive symptoms of adult children. In addition, the last finding was that there was no significant difference between dysfunctional attitude among parent having children with intellectual disability and without intellectual disability with respect to their demographic variables age, gender, education and income. <sup>(5)</sup>

**Lone A. I (2013):** The study highlights the causes, consequences and rehabilitative measures among people in general up to the age of 10-60 years. First, disability has various causes some are by birth (hereditary) some are after birth e.g., accident in factories, road accident, mental tension, building crush, exchange of firing etc. Second, disability has considerable consequences on individual, family and society. Person of disability feels loneliness, boundless into four walls, economically dependent and medically not treated; unable to work if his/her arm or leg is to be amputated. Socially, their contact becomes limited and psychologically the depression occurs in them. Finally, rehabilitative measures should provide in the name of disabled persons of all sections of society especially weaker sections, penniless and needy people. In an attempt to study the causes, consequences and rehabilitative measures among all strata of society. It examines the impact of different types of disabilities on general population between the age group of 10to60 years. The area/universe for the present study was taken as district Srinagar of Kashmir valley. Interview schedule and observation seemed to be the best possible methods as tools and techniques. <sup>(6)</sup>

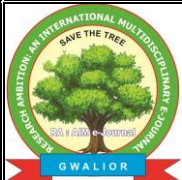
**Kawa M.H. and Shafi H.(2013):** The present study is an effort to assess stress and depression among parents of mentally retarded children. The sample for the study consisted of sixty (60) parents of children with mental retardation, out of which twenty two (22) were fathers and thirty eight (38) were mothers selected randomly from various institutions working for these children from district Srinagar. To assess stress and depression among these parents family interview for stress and coping (FISC - MR) and Aron Beck's Depression Inventory (BDI-II) were used as tools for the study. The



obtained data were analyzed by frequency method, Pearson correlation coefficient method and t-test. Finally, the results indicate that mothers experience more stress and depression as compared to fathers. Also a significant positive correlation was found in stress (daily care stress, family-emotional stress, financial stress, social stress) and depression in mothers of children with mental retardation. The study revealed that the stress and depression has an extensive influence on parents especially on mothers of mentally retarded children. <sup>(7)</sup>

**Bashir A. and Ganaie Z.A (2013):** Studied that disability is usually referred to as an individual's disadvantage. Helping a person with disability is perceived as an act of distribution of benefits and sharing of burdens. Persons with disabilities make up a significant part of the world's population an estimated 1 in every 10 people, amounting to 650 million people (UNFA REPORT 2009). The study mainly focuses on; to assess the various programs for the persons with disabilities in Jammu and Kashmir, to critically analyze the disability programs in Jammu and Kashmir and to suggest measures and recommendations for the welfare of persons with disabilities. In India stern efforts have been taken to improve the health and status of persons with disabilities in family and society. At present in the state of Jammu and Kashmir, programs and policies for persons with disabilities are limited. Proper planning is lacking in Jammu and Kashmir towards the upliftment and rehabilitation of persons with disabilities. Little awareness and sensitization is among the general population regarding the rehabilitation services of persons especially children with disabilities in Jammu and Kashmir. Vulnerable groups of society living in areas where proper facilities are not available undergo suffering at numerous levels. <sup>(8)</sup>

**Kawa M. H and Shafi H (2015):** The present study was conducted to investigate the religious orientation and psychological distress as well as to find out relationship of religious orientation with psychological distress among parents of mentally retarded children. Parents of mentally retarded children were also compared on religious orientation and psychological distress with respect to their gender. The data for the present study was obtained from parents of mentally retarded children [N=200 (Fathers 90 & Mothers 110)] belonging to various districts of Kashmir valley. The collected data was analyzed by using appropriate statistical techniques like Pearson's product moment correlation and t-test. The results showed significant negative correlation between intrinsic religious orientation and psychological distress. Moreover, a significant positive correlation was found

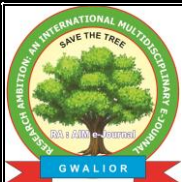


between extrinsic religious orientation and psychological distress. Later on the researcher used purposive sampling and communicated with the parents of these mentally retarded children and sought the consent from them for participation in the present study. Religious Orientation Scale (1983) and Kessler Psychological Distress Scale (K10) 1996 were used as tools. The information/responses collected from the respondents were subjected to various statistical treatments. The data was analyzed by using Statistical Product and Service Solutions (SPSS 16.0). Statistical techniques used for analyzing data were: frequencies, percentages, correlation and *t*-test.<sup>(9)</sup>

**Maqbool B and Hariharen P. (2017):** The present study mainly focuses on the scenario of disability programmes in Jammu and Kashmir in which the persons with disabilities face many problems with respect to education, accessibility, employment, certification, and rehabilitation. There is lack of special schools, integrated and inclusion is so far from the state. As per census 2011 J&K has around 3.61 lakhs population of persons with disabilities with 18.3 lakhs persons with blindness, 20.5 lakh persons with hearing disabilities, 5.1 lakhs speech disabilities, 16 lakhs persons with physical disabilities, 4.6 lakhs with mental retardation and around 4.3 lakh persons with mild to severe mental illness. The scenario of disability and programs in J & K reveals that there is an immediate need to focus on the disability sector in terms of sudden proliferation of disability rate, employment, education and training, social security, rehabilitation, professional development etc. The governance strategies of the state must be considerate towards the welfare of the people of the state. Increasing awareness and research to identify best practices in disability rehabilitation are prime requirements in these times.<sup>(10)</sup>

**Ahmad S.N et. al(2017):** This study was done on cerebral venous sinus thrombosis (CVST). It has a variable presentation making early diagnosis difficult. The study was aimed to find out the clinical, etiological and prognostic of CVST in Kashmir. The study was carried out in a tertiary care hospital where all patients of CVST admitted between 1st August 2014 and 31st July, 2016 were included in the study. A total of 36 patients of CVST were included in the study. The mean age of the patients were 35 years old with highest representation (38.89%) among 31-40 years age group. Headache was present in 94.4%, 30 patients (83.3%) were alive at the end of follow-up and 6 patients died (16.6%). Among various etiological factors purpuration has a maximum representation (33.33%), Out of 32 female patients in the study group, 16 (44.44%) female patients had purpuration and 06 (16.66%) had





oral contraceptive as a risk factor. Unconscious with purposive movements was observed in 27.78 % of the subjects. Out of 39 patients who survived, 31 cases (79.4%) had no disability symptoms, 5 patients had mild disability (13%) and 3 patients had moderate disability at six months of follow-up. Purperium appears to be the main etiological factor and headache as the most common system for CVST in study population. <sup>(11)</sup>

## Objective of study

1. To study the impact of disabled children on the growth and development of family.
2. To assess the behavior of family members and society towards the disabled children.
3. To aware people about various schemes of government towards the welfare of the disabled children.

## Research methodology

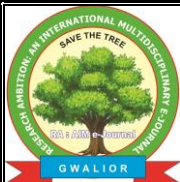
The study was conducted on the (disabled children and their impact on family) in Kulgam district of Jammu and Kashmir. For the purpose of seeking information from this study, various families of disabled children were visited. The tools used to facilitate collection of data was the interview method and self-developed questionnaire. The sample was selected randomly. Children having any type of disability were chosen. The obtained data was compiled and analyzed using simple statistics.

## Result and discussion

**Table 1: Children's having learning disability in their families**

| S. No. | Options                  | Frequency  | Percentage  |
|--------|--------------------------|------------|-------------|
| 1      | Learning disability(yes) | 8          | 4%          |
| 2      | Learning disability(no)  | 192        | 96%         |
| Total  |                          | <b>200</b> | <b>100%</b> |

Table 1 show that 96% of the respondents did not have any learning disability or any other type of disability present in their families. Only 4% respondents have some learning disability or some other type of disability present in their families. Thus it has been found that majority of the



respondents did not have any type of learning disability or any other disability in their families. Parents did not have any type of disability but the new inborn were disabled.

**Table 2: Facing financial problem while caring of disabled child**

| S. No. | Options                        | Frequency | Percentage |
|--------|--------------------------------|-----------|------------|
| 1      | Facing financial problem       | 144       | 72%        |
| 2      | Did not face financial problem | 56        | 28%        |

Table 2 indicates that 72% respondents of the disabled children were facing the financial problems while caring their disabled children and 28% respondents did not face any kind of financial problems. Since, majority of the respondents were farmers having very low income that is why they were facing this kind of problem. Further, majority of the respondents of the present study were rural and were unaware about various government schemes.

**Table 3: Disability is a burden on parents**

| S. No. | Options              | Frequency  | Percentage  |
|--------|----------------------|------------|-------------|
| 1      | Burden on parents    | 32         | 16%         |
| 2      | No burden on parents | 44         | 22%         |
| 3      | Don't say            | 124        | 62%         |
| Total  |                      | <b>200</b> | <b>100%</b> |

Table 3 indicates that 16% of the disabled children were burden on their parents, 22% disabled children were not burden on their parents, and 62% of children's parents didn't answer this question. The result shows that some respondents did not agree that their disabled child is burden upon them while some respondents agree and mostly the respondents keep silent. Different people have different nature and it depends up on the nature of the respondents how they behave with their children and how they face the problem of disability.

**Table 4:-Attitude of other children in the family**

| S. No. | Options  | Frequency  | Percentage  |
|--------|----------|------------|-------------|
| 1      | Positive | 28         | 14%         |
| 2      | Negative | 80         | 40%         |
| 3      | Neutral  | 92         | 46%         |
| Total  |          | <b>200</b> | <b>100%</b> |



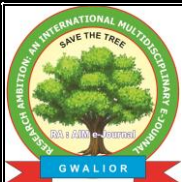


Table 4 shows that 14% of normal children in the family have positive attitude towards the disabled child, 40% have negative and 46% have neutral attitude.

This indicate that majority of the normal children's have neutral attitude towards the disabled child. But there are some normal children who have negative attitude towards the disabled child; it mainly depends on type of family and the atmosphere of the family.

**Table 5:- Feeling upset due to disability of child**

| S. No. | Options | Frequency | Percentage |
|--------|---------|-----------|------------|
| 1      | Yes     | 196       | 98%        |
| 2      | No      | 4         | 2%         |
| Total  |         | 200       | 100%       |

Table 5 shows that 98% parents are upset with the way their child's life is going and 2% parents did not worry about their child's life. This shows that majority of the parents feel upset with the way their child's life is going on. They feel that disability is a big problem for their disabled children and they will face different barriers during their life time.

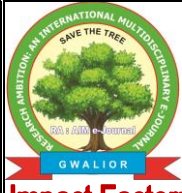
**Table 6:-Use any government scheme for disabled child**

| S. No. | Options | Frequency | Percentage |
|--------|---------|-----------|------------|
| 1      | Yes     | 8         | 4%         |
| 2      | No      | 192       | 96%        |
| Total  |         | 200       | 100%       |

Table 6 indicates that 96% respondents did not use any government scheme for their disabled children and only 4% respondents use some government schemes. Which indicates that majority of the respondents did not use any Government scheme for their disabled children. It means that the Government did not provide schemes to the disabled children or mostly people are from rural areas and are unaware about such schemes.

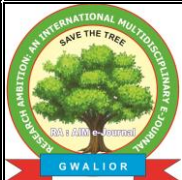
### Findings and suggestions

The preceding discussion about the disabled children and their impact on family indicates that disability is a big problem. Since Children's are the human resource and assets of a country. Disabled



children are the most vulnerable section of our country and they need special care and protection, if the future of the nation is to be made secure. Certain services must play an increasingly important role in future by providing the support necessary to facilitate the development of disabled children mentally as well as physically.

- Special care centers should be established which could provide day care facilities for the disabled children and can give some relief to the parents from their emotional and physical stress.
- The communities themselves should take an initiative in establishing some special care centers and self-help groups (SHGs) which they could only do with the guidance from professionals like social workers, community doctors and nurses. The availability of these professionals could bring light especially in matters of fund-raising both from the government and some private sources and even from the community itself and how to start a self-help project.
- There should be an improvement of the existing services for the disabled children and their families like appointing more social workers in each district so that adequate attention could be given to each family for effective social work service.
- Establishment of clinics should be done in all areas for an easy access to the family especially in times of crisis.
- The provision of special schools with all the necessary equipment and the general improvement of the standard of the school, all would have a considerable positive effect on the quality of life of the family and the disabled child. This would also help the disabled children with self-help skills.
- The disabled children's psychological barriers should be reduced by effective education.
- Government should create opportunities for broader spectrum of jobs for people with disabilities.
- Disabled people should be provided with loans and financial support for small entrepreneurs to create workplace, equipment and tools as well as some small scale and house hold industries.
- There should be equal opportunities, equity and social justice to persons with disabilities.
- There should be implement outreach and comprehensive Community Based Rehabilitation programmes in urban and rural areas.
- The scope of vocational and professional opportunities, income generation and gainful occupations should be enlarged.



- There must be the support of legal literacy, including legal counseling, legal aid and analysis and evaluation of existing laws.
- Facilities like sports, recreation, leisure-time activities, excursions, creative and performing arts, cultural and socially inclusive activities should be supported.
- Not only government but private charitable agencies must make available prosthetics, aids and other helpful services to the differently-abled people.
- NGOs should be involved in organizing disabled parent clubs and meets to develop warm, trusting relationship with their disabled children and they should be involved for the welfare and assistance of disabled children.
- The education service i.e. the initiating of a special school for the disabled children needed to be developed and improved. This would make a marked improvement in the lives of these children and their families.

## Conclusion

The study was conducted to explore the perception, knowledge and impact of disabled children on the family in district Kulgam, Jammu and Kashmir. Since the birth of a child is normally viewed with eager anticipation. As parents make preparations for the birth of their child, they may not only wonder about the gender of their child, their child's eye color, or appearance, but also hold expectations for what this child will become in the future. When a child is born with no complications or disabilities, this process seems to evolve naturally. However, when there are prenatal complications or postnatal discoveries of developmental disabilities, the idealized picture of having a normal child is shattered. According to [Turnbull and Turnbull \(2001\)](#), parents of children with disabilities may experience a grief cycle that is similar to that of the death of a loved one. Disability is the consequence of an impairment that may be physical, cognitive, mental, sensory, emotional, and developmental or some combination of these. A disability may be present from birth or occur during a person's lifetime.

The results of this study provide some evidences that the type of child's disability is related to particular family outcomes. Families whose children have conditions that change or worsen over time are affected by worry about the child's physical and emotional health. Families whose children have physical limitations (causing high caregiver burden) acknowledge greater interruptions and



limitations in their normal life. Majority of the families were facing financial problems while caring their disabled children because they were the only sources for their children for providing care. There are not any other agencies like NGOs through which they can take help or some assistance for caring their disabled children.

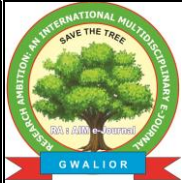
The disabled children were not receiving equal opportunities in terms of education nor were they taking any special services from the school system. In whole Kashmir valley, the education system for such children is far behind (when compared to different states of India). There are no special tutors for such children. Today whole world is taking advantage of Braille technique except Kashmir, where only two-three percent of such children go to school. At the moment, there is one special school that is run by government at Composite Regional Centre for rehabilitation of persons with disability (CRC), in Bemina area of Srinagar. The absence of adequate government-run schools for differently-abled children also flies in the face of the 1998 Disability Act, which explicitly states that government has to guarantee rehabilitation and education to the children with disabilities.

The normal children, both in the family as well as in society showed negative attitude towards the disabled children. The disabled children were being teased and mocked with different names in Kashmiri language and different labels were used for these children. Almost all the children were taking most time for the respite care that is why the families were facing limitations for performing domestic as well as other tasks.

Since the research was done in rural areas of Kashmir, so majority of the families were deprived of using any Government scheme and most of them were unaware of schemes of the Government. Somehow, if any family were using any kind of such scheme, they were not satisfied with assistance of the Government. The families were worried about the future care of their disabled children and they expressed their wish to have special services and schemes for their children.

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