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# Challenges of Parents with Two Intellectually Disabled Children

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## Abstract

This study was conducted to assess the psycho-social problems faced by parents with more than one intellectually disabled child in Mangalapuram Panchayath of Trivandrum District, Kerala. The psycho-social elements considered for this qualitative study includes emotional adaptability of parents, the role of support systems and the precautions taken by the family after the birth of the first child. Data were collected from 5 cases selected from the 15 cases identified in Mangalapuram panchayath. The cases were purposively selected from parents having minimum two disabled children. Data were collected using a semi-structured interview guide as a tool. The difficulty faced by the families with two disabled children reveals multiple levels of stress when compared to families with typically developing children. Such families face problems ranging from financial aspects to the physical, psychological and social aspects, which in turn affect their quality of life.

**Keywords:** Disability, Children, Emotional Adaptability, Support System

## 1. Introduction

Everything has its wonders, even darkness and silence, and I learn whatever state I may be in, therein to be content." - *Helen Keller*

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One billion people or 15percent of the world's population, experience some form of disability, and disability prevalence is higher in developing countries. One-fifth of the estimated global total or between 110 million and 119 million people experience significant disabilities (The World Bank, 2017). In India, 2.21 percent of the total population has atleast one kind of disability. Locomotor and multiple disabilities are more commonly found in rural areas of India. Speech and hearing impairment is found to be more prevalent among the urban population of India. In the case of India, leaving persons with disabilities out of economy translates into a loss of about 5-7percentof GDP (Kumar, 2017).

It is no secret that raising a child with disabilities can affect family life in many ways both positively and negatively. Children with intellectual and developmental disabilities present unique parenting challenges that may be stressful to caregivers but may also bring out positive feelings such as empathy, gratitude and an increased sense of purpose and priorities (Hastings & Taunt, 2002).

According to the definition given by World Health Organization (2011), 'disabilities' is an umbrella term, covering impairments, activity limitations, and participation restrictions. Impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations. Disability is thus not just a health problem. It is a complex phenomenon, reflecting the interaction between features of a person's body and features of the society in which he or she lives. The major causes of intellectual disability, proposed by mental health professionals and doctors, include genetic conditions, pregnancy issues (malnutrition, infections of the mother, environmental toxins etc.), issues during childbirth (premature birth and low birth weight), problems after birth (childhood diseases, head injury etc.), poverty and cultural factors (diseases, malnutrition) (Gluck, 2016).

Societies' treatment of individuals with disabilities has changed throughout history. In the UK, during the 15<sup>th</sup> century, the society and the church viewed disabled persons as supernatural individuals who were against God. However, advancements in the medical field have eventually led to the diminishing of these

superstitious ideas. Later, laws were passed called the Elizabethan poor laws (1601) in which people with disabilities were labelled as “helpless poor”. Methods have been discovered to prevent developmental disabilities such as providing proper nutrition for the pregnant mother and newborn babies (Zastrow, 1999). December 3<sup>rd</sup> is celebrated as the international day of persons with disabilities promoted by the United Nations since 1992. The theme for 2016 was “to achieve 17 goals for the future we want”. Their major plan is to conduct forums and public discussions, information campaigns, public rallies, art shows, exhibitions etc. They also raise the awareness about the 2030 Agenda for Sustainable Development and Sustainable developmental Goals (Clubmates Travel, 2016).

## **2. Impact of Having a Child with Intellectual Disability on Parental Well-Being**

Caring for a child with disability brings multiple challenges to parents, such as additional financial burdens (Jung Hwa Ha, 2012) for treating their child’s condition, dealing with the child’s problematic behavior, and social stigma associated with disabilities (Baker & Heller, 1996; Lecavalier, Leone, & Wiltz, 2006: 175). Financial strain is one of the most prominent sources of stress in many families with Children with Disabilities (CWDs). Families having CWD are significantly more likely to live in poverty than families that do not have CWD (Parish SL, Cloud JM., 2006:1). Mothers of children with intellectual disability are more stressed than mothers of typically developing children (Eisenhower, Baker, & Blacher, 2005). Financial strain is one of the most prominent sources of stress in many families with Children With Disabilities (CWDs). Parents emphasised the need to be physically and emotionally healthy to properly look after their child. Lifting, sleep problems, and the chronic care and supervision needs of the child where some of the factors that threatened parents’ physical and emotional wellbeing. To maintain physical wellbeing, suitable housing, short-term care and skills in dealing with their child’s sleep problems were seen as important. To promote their emotional wellbeing parents wanted to feel that the responsibility for their child was being shared with formal support services. More

specifically, professional counselling support and contact with other parents were identified as important outcomes for parents with disabled children (Beresford, Rabiee & Sloper, 2007).

Parents of CWD also have reported that the more time they spend to care for their child, the more burden they feel. Haveman et al. (1997) found that the time demands averaged 31 to 60 hours a week for parents with children less than nine years of age and 15 to 30 hours for parents with an adolescent or an adult. The time demands were greater for families who had a child with fewer adaptive skills, more behavioural problems, and more physical health problems. Those families who had older children with more severe behavioural problems, worse physical health and fewer adaptive skills reported to have higher levels of burden (Haveman et al., 1997).

Consequently, parents of children with a disability often experience more physical health symptoms, negative effect, and poorer psychological well-being than parents without a child with disabilities (Jung Hwa Ha, 2012, p. 4).

## **2.1 Parenting a Child with Disability**

Children with disabilities require much parental attention, which increases parental stress. The parenting style, family dynamics and environmental factors are important for understanding, assessing and managing children's disabilities (Jung Hwa Ha, 2012, p. 127). The findings of the study *Parenting Style and Parents Level of Stress Having Children with Autistic Spectrum Disorder* conducted by Nishi Tripathi (2015) indicates that the mothers tend to use a more permissive form of parenting in comparison to the fathers. The parents with children having a severe form of autism spectrum disorder used authoritarian parenting style. The results also showed that most of the parents were having a high level of stress hence proper counselling therapy and training should be provided for parents for the most appropriate form of parenting style (Tripathi, 2015). A study conducted by Gallagher, Phillips, & Carroll (2009) reveals that parental stress is associated with poor sleep quality in parents of children with developmental disabilities. The monitoring and management of sleep issues in these parental caregivers should be a priority for health professionals.

## 2.2 The Role of Social Support and Coping Strategy

As most of the CWD exhibits problematic behaviour, it is important that families adopt appropriate and effective coping methods in adjusting to their child's condition. A study conducted by Amy Pritzlaff (2001) suggested that family integration, support, and a positive definition of the situation, in addition to maintaining self-esteem, psychological stability, and social support most effectively helped parents adapt to the stress of managing a household with the addition of a child with an illness. Intellectually disabled children experience considerable challenges in two primary areas: Adaptive behaviour and intellectual functioning. Adaptive behaviour involves the use of everyday life skills. The common characteristics of intellectual disabilities: difficulty in learning and processing information, problems with abstract thought and problems with social interaction occur at varying levels unique to each individual. (Gluck, 2016). Parents of CWID (Children with Intellectual Disabilities) must cope with stress within the context of their interpersonal relationships with one another. In the context of raising a child with a disability, a few studies have found that parents with greater social support show positive parenting behaviour (Ha, 2012, p. 406).

Support from partners and related family members have shown great influence in the well-being of parents of CWD. Bennett, DeLuca and Allen (1995) found that parents in all stages of the family life cycle perceived family members and close friends as sources of emotional support. Parent support groups appeared to be the largest source of social support that parents receive from people outside of their immediate family. These groups can be sources of emotional support, as well as sources of information and techniques about caring for a person with a disability. For some parents, the level of burden they experience is directly affected by the levels of frustration and lack of support from outside sources. Often, the more support received, the more it leads to the perception of a greater level of functioning and coping. Jung Hwa Ham (2012) found that outside services such as support groups, in-home services, and respite care reduced the level of frustration for parents. The four major models used to understand disabilities are:

- Medical Model: which views impairment as a problem located in an individual
- Human Rights Model: accords fundamental human rights to persons with disabilities
- Social Model: makes a distinction between impairment(physical, mental, sensory) and disability (as the experience of social oppression)
- Critical disability Study (CDS) Model: questions the dualism between impairment and disability (Berghs M et al. (2016).

### **3. Methodology**

This study was conducted in Mangalapuram Panchayath of Thiruvananthapuram district. This is a qualitative study to understand the psycho-social problems faced by parents with two intellectually disabled children. The psycho-social elements considered for the study includes emotional adaptability of parents, the role of supporting systems and the precautions taken by the family after the first child.

The research questions were:-

1. What are the ways the parents have emotionally adapted to the situation of handling two intellectually disabled children?
2. What are the styles and patterns adopted by parents to raise the intellectually disabled children?
3. What is the role of support systems?

These questions were central to the study. The study also aimed to understand the socio-economic background of parents.

Disability is a complex phenomenon, reflecting the interaction between features of a person's body and features of the society in which he or she lives. The difficulty faced by the families with disabled children reveals a higher level of stress in the family system when compared to a control group of families with typically developing children. Family dynamics suffers mobilisation, ranging from financial strains to aspects related to the

physical, psychological, and social quality of life. This study helps to find out the socio-economic problems faced by parents having two disabled children in the family, their parenting experience, precautions taken after the birth of the first child and the emotional adaptability of the parents. Even though many researchers have studied the different dimensions of disability and its impact, only a few attempts have been made to explore the area of understanding the problems faced by parents raising more than one intellectually disabled child. So the gap was identified, and the relevance of focusing our study on the socio-economic problems faced by parents with two intellectually disabled children in the family was really felt.

As a first step, the researchers, using the census method, identified all the families having two intellectually disabled children in Mangalapuram panchayat. And by analysing this data, the researchers could understand that in the majority of the families, disabilities were identified among siblings. From this, five samples were selected using critical case sampling from mothers with two intellectually disabled adolescent children and having a family history of disability. The semi-structured interview guide was used as a tool for collecting data, and the respondents were given pseudonyms.

### **Case 1**

Mrs Anitha, 38 years old, married to her first cousin, has two intellectually disabled children with the age difference of just one year. Both are having more than 50% of mental retardation. Both of their disability was identified during their early childhood itself. She was not very satisfied with the emotional support provided by the spouse. The relatives showed only negligence and did not provide them with emotional or financial support. In the case of her second pregnancy, she was not expecting a child as she was breastfeeding the elder child and was not physically and mentally prepared for it. She came to know about the pregnancy only after her sixth month. So she was blaming herself for being ignorant and not taking appropriate precautions and medicines for the second delivery. Gradually the couple started to believe that they have to accept what God has given them without any choice. For her,

taking care of the second child was more difficult and fearful; since the second child is a girl, she is stressed about the menstruation and personal hygiene and is afraid how the child will take care of herself.

As a parent, it was really difficult to take care and give attention to both of them at the same time. The children were unable to carry out their daily routines (taking food, toileting, bathing, and personal hygiene). Due to financial constraints, the family was not able to provide proper education and treatment for the children.

No particular mental and physical preparations were taken by her during the second pregnancy. Even though the child had visible developmental delays, no particular complications were noticed during scanning. And after childbirth, when the disability was noticed the mother opted for allopathic treatment.

## **Case 2**

Mrs Bindhu, 42 years old has two intellectually disabled children with 50 percent of Mental retardation. The children have an age difference of 2 years, and both their disability was identified in their early childhood itself. It was noted that the disabled children's grandmother had a mental illness which shows they had a family history of mental illness. The parents married, late in their life and the first child was born with complications. Since the disability was identified in the first child and owing to the economic constraints, family members had pressurised her to abort the second child when she was pregnant. It increased the psychological stress in her. However, no precautions were taken by her during the second delivery. The first child had faced challenges in development, but in the case of the second child, the disability was identified by the class teacher, but the parents were not ready to accept the fact that their second child was also mentally disabled. They also did not provide any particular treatment to the child. Mrs Bindhu had poor emotional support from the spouse and close relatives after knowing that the second child is also intellectually disabled. The children were more attached to her, so she had to take care of both even in doing their daily routines. The parents were not aware of the facilities provided by the special schools neither did they know the importance of providing education to their children.



### Case 3

Mrs Radha, 36 years old, has two intellectually disabled children with an age difference of two years. Both of them are affected with mental retardation (MR), the elder child with 45 percent of moderate MR and the younger one with 35 percent of mild MR. Disability of both the children was diagnosed lately during their elementary school). Both the children were not provided with any particular treatment or therapies even after the diagnosis because of economic instability, and they were also ignorant about the different treatments that can be provided to the children. The parents had no family support because theirs was not an arranged marriage. So it was really difficult for the parents to take care of both the children without any emotional and financial support from the family members. They have a family history with mental retardation. During the first delivery, the Mrs Radha had a certain complication (increased blood pressure, fever) so she was asked to do the caesarean. She took no particular precautions for second pregnancy. When asked about the difficulties they talked at length about the economic, social and psychological difficulties they confronted. The family is not in a condition to meet the needs of both the children and the parents are so much worried about their education and future. It was also observed that she had difficulty to accept the fact that their children are mentally retarded and they are in need of proper treatment.

### Case 4

Mrs. Shyamala, 44yrs old, has two male children with intellectual disability just with the difference of 2 years. Her husband Madhavan is her grand mothers' brothers' grandson. The eldest child is having speech disability, which was diagnosed during the scan in 7<sup>th</sup> month. The youngest child is having 80 percentage of mental retardation (cerebral palsy), it was diagnosed when the child was one year old i.e., when the developmental milestones were not achieved. There was no particular delivery complication at the time of first and second delivery. She had shown the symptoms of mental illness and she was taking medication during the conception of the second child which has been suspected by them to be a reason for the child being mentally retarded. The father is taking care of these two children and the mother is not

able to look after the children because of her mental illness. This increases the burden and he is not getting proper support from their relatives, and even at the time of hospital appointments there was no one to accompany them. As the father is the main source of income to the family, in most days the children are been looked after by the grand-mother who is 75 years old with lots of health issues. Economically, the family felt it difficult to meet the needs of children, especially for the transportation to hospitals, as there is no road facility. The children receives disability pension from the panchayat.

### **Case 5**

Mrs. Sushama, 39yrs old, has 4 children and the third and fourth are having intellectual disability. They are of 2 years age difference. Both of them are having hearing and speaking impairment, in which the disability of first child was diagnosed during early childhood and second child during late childhood. Certain developmental delay was noticed in the first child and not in the case of second child. No particular precautions were taken by the parents for the second delivery. The parents had consanguineous marriage and they were first cousins. The children find difficulty in following the educational syllabus. So they discontinued it and looked forward for special school training and this led the parents to think of the seriousness of the disability the children had. The family was stigmatized by the society as they curse the parents that their carelessness led to the disability of the children. As both of the disabled children were adolescent girls, she was so much worried about their menstruation and personal hygiene. The family is financially poor and they find difficulty even to pay the house rent of rupees 2000/- per month. As they do not own a house, the security of these children after the death of the parents is their great concern. The family receives psychological support from Anganawadi worker and financial support from panchayat as disability pension.

#### 4. Data Analysis

| Questions                                     | Case 1<br>(child1,<br>child 2)               | Case2<br>(child1,<br>child 2)              | Case3<br>(child1,<br>child 2)             | Case 4<br>(child1,<br>child 2)                      | Case5<br>(child1,<br>child 2)                              |
|---|--|--|---|---|--|
| Disability diagnosed                          | Both were diagnosed during early childhood   | Both were diagnosed during early childhood | Both were diagnosed during late childhood | First child-prenatal period<br>Second child-infancy | First child-early childhood<br>Second child-late childhood |
| APL/BPL                                       | APL  | APL  | APL                                       | APL   | BPL  |
| Location                                      | Korani, Rural                                | Chembaka mangalam , Rural                  | Thonakka, semi-urban                      | Venghod, rural                                      | Shastavattom, semi-urban                                   |
| Occupation of the husband                     | Coolie                                       | Auto driver                                | Mason                                     | Coolie  | Coolie   |
| Caste   | SC   | OBC  | OBC                                       | OBC   | SC   |
| Class   | lower  | lower                                      | lower                                     | lower   | Lower  |
| Delivery complications                        | No   | Yes(child1 )<br>No (child 2)               | Yes for both the children                 | Not in both children                                | Yes in first child and not in second child                 |
| Age of mother during her first delivery       | 23   | 32   | 24  | 23  | 28   |
| Age difference between first and second child | 1 year                                       | 2 year                                     | 2 years                                   | 2 years   | 1 year   |
| No: of scans during second pregnancy          | No scans were taken                          | One  | Three                                     | No scans were taken                                 | Three  |
| Developmental delay                           | Both had developmental delays noticed during | First child had developmental delay.       | Both had developmental delays             | Both had developmental delays                       | First child had developmental delay.<br>And no             |

|                               |  |  |   |  |  |
|-------------------------------|--|--|---|--|--|
|                               | early childhood  | And no developmental delay was noticed in the second child   |   |  | developmental delay was noticed in the second child                            |
| Stream of medicine            | Both opted for allopathic  | For the first child allopathic was followed and they never consulted a doctor for their second child | Both took allopathic medication                                     | Both took allopathic medication  | Both opted for allopathic  |
| Normal/cesarean               | Both normal delivery   | Both normal delivery   | Both cesarean   | Both normal delivery   | First child-Normal<br>Second child-Cesarean                                    |
| Need assessment (observation) | Economic support. Future and career aspects for the children                                       | Transportation difficulty and poor financial condition   | Transportation difficulty, poor economic condition                  | Poor Economic condition and transportation difficulty  | Need for special school education  |
| Profile of the school         | Both the children were sent to rotary institute for children in need of special care, vazhuthacaud | Both the children were sent to normal schools but was not able to continue the studies               | Both the children were sent to BUDS special school, Medical College | The first child was sent to BUDS School and the younger one was not provided with any schooling. | Both the children were only provided with primary education in normal schools. |

All the five cases belong to lower class. They all approached government hospitals for their medical needs. It is also seen that all children had timely immunization. In all the cases there is a family

history of intellectual disability, and it increases the chance of getting disability to the family members of other generation (Gluck, 2016). Four cases included in priority list (APL - Above Poverty List) and only one family is included in non-priority list (BPL- Below Poverty List). But the researchers identified that all the five families are financially poor and they all require financial support and should be benefited under non- priority list. In three cases, parents are illiterate and could not identify the disability of the children initially, which lagged the treatment. Only in one family the children are sent to special schools, some parents are not even aware of this educational system and some denied it because of the poor financial condition. Consanguinity is a well-known risk factor for genetic disorder. In majority of the cases (3 cases) consanguineous marriage was practiced. No precautions were taken by any of the families after first delivery and there was only 1 to 2 years of age difference between the first and the second child. All the children are fully immunized, the parents opted allopathic stream of medicine in all the cases.

## 5. Findings

By analyzing and observing all the five cases in detail, the researchers could find that:

- Intellectual disability is a severe handicap that affects between one and two percent of children worldwide. It can often be attributed to genetic causes, but the specific genes involved were mostly unknown (University of Montreal, 2011). In all the cases a prevalent family history was present which shows the influence of genetic factors in causing disability. An estimated 15 million babies are born premature too early every year. Approximately one million children die every year due to complications of preterm birth. Several survivors face life time disability or disabilities (WHO, 2017). In this study, out of 10 deliveries covered 4 had delivery issues.
- Consanguinity is a well-known risk factor for genetic disorder. The consanguineous marriages may be playing a crucial role in transferring ID (intellectual disabilities) in

children from their ID relatives and primarily, consanguinity is a social factor (Lakhan R et al. 2017). Out of 5 total cases, in 3 cases consanguineous marriage was practiced. Further research is needed to better understand the association between ID and family history. There is also need to create public awareness related to ill effects of consanguinity and its association with ID. Public education has to be undertaken to instill the biological risk of close marriage.

- In all the cases the age difference between the two disabled children were between 1 to 2 years, which can be considered as a triggering factor for increasing the disability for the second child especially when the parents refuse to take precautions for second pregnancy.
- Early diagnosis can reduce the severity of any kind of disability. Individuals with ID have high rates of psychiatric co morbidities. However, diagnostic difficulties due to atypical presentations, diagnostic limitations secondary to communication barriers, and lack of formal diagnostic tools are inherent in this population. Studies show that the diagnosis of psychiatric disorders in the ID population is affected by language skills and the severity of ID (Aggarwal, Guanci, & Appareddy, 2013).
- Here, majority of the cases were lately diagnosed with intellectual disability especially during early and late childhood with certain developmental delays.
- Majority of the intellectually disabled children fall under the moderate to severe range. These categories are trainable and in some situations educable too. But because of the poor economic conditions and lack of proper awareness the parents were not able to provide proper treatment which reduced the chances of improving the conditions of these children.
- Caring for a child with a disability bring multiple challenges to parents, such as additional financial burden for treatment purposes, adapting proper coping strategies

in handling the child's problematic behavior, and facing the social stigma associated with it.

- Authoritarian style of parenting was universal in all the cases studied that the children cannot figure out things alone. Permissive parents are sometimes accepting and not demanding. The approach of the parents towards children with developmental delays has a direct bearing on how cooperative and independent these children become when they grow up.
- The researchers were able to understand the helplessness of the parents, in choosing the appropriate parenting style. Because of the fluctuating behavior shown by the children the parents are practicing situation based parenting.
- In majority of the cases it was the sole responsibility of the mother to take care of the disabled children which is affecting their normal social, physical and psychological functioning and in one case when the father had responsibility to look after the children, it had affected the functioning of the whole family as he is the only source of income to the family. From this, the researchers felt that the caregivers should be acquainted with the importance of self-care.
- The support system plays a major role in strengthening physical, mental and social wellbeing of people. In all the cases the respondents were not having proper support system from the family members, society and even from the spouse. This condition leads to burn out and compassion fatigue among the caregivers.
- Even though majority of household comes under priority category, from their economic background, it was observed that they should be included in the non- priority category.
- All the cases were having disability certificate and they also received disability pension.
- Because of poor awareness among the parents, financial instability, lack of proper transportation facilities and poor

social support system majority of the parents are not sending their children to special school.

- As in the Kubler- Ross DABDA model of grief most of the parents after passing through these first 4 stages (denial, anger, bargaining, and depression) have now become emotionally adapted to the situation. And the researchers could find that their helplessness forced them to be emotionally adapted to the disability of their children.
- The stigma towards disability was evident when the parents faced discrimination, inferior treatment and social isolation. As both the children were suffering from intellectual disabilities most of the parents decided not to have another child. The researchers were able to identify the causation guilt and role guilt that the parents had and the parents felt that they had not done enough on their part.

## 6. Conclusion

The interpretation of the data revealed that, the parents of differently abled are feeling insecure regarding the children's long-term quality of life due to lack of formal supporting system. In all the cases a prevalent family history was present which shows the influence of genetic factors in causing disability. The existence of a child with disability is affecting their everyday life, but families somehow adjust and adapt to these situations. All the parents have already passed through the denial, anger, bargaining to live, depression stages and now they have accepted and became emotionally adapted to the situation. Authoritarian parenting style was universal in all the cases. It is also felt that, the state should provide laws and policies that are disability oriented as well as educate the community regarding the types of disabilities, in order to make changes in their attitudes and to reduce social as well as self-stigma.

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