

Research Paper

Challenges faced by parents of disabled children at Khulu Malang Memorial School with Special Needs, Thadlaboh Tyndowapung Jowai, West Jaintia Hills District, Meghalaya

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ABSTRACT

Parenting is undoubtedly one of a difficult task to undertake. It becomes even more challenging when the child happens to be one with a disability. We can only speculate from the surface the difficulty that parents or caretakers have to undergo. This study as such focused on the challenges faced by the parents of disabled children. The area of study is based solely at one particular school named **Khulu Malang Memorial School with Special Needs, Tyndowapung Jowai, West Jaintia Hills District of Meghalaya**. The main objectives of this study is (1) To identify the challenges faced by parents of children with disability, (2) To examine the affects that parents experienced, (3) To identify the facilities provided by the Government for children with special needs. This research study is a mixed method employing both qualitative and quantitative approaches. This study comprised of 20 respondents (*19 female and 1 male*). According to the findings, it indicated that most of these respondents face difficulties in relation with time management, psychological issues, financial problems, and anxious about future.

Keywords: *Challenges, Parents, Disabled, Children, Khulu Malang Memorial, Special Needs.*

Disability: A Brief Overview

Disability is a physical or mental impairment that substantially limits one or more major life activities, such as caring for oneself performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, learning, reading, concentrating, thinking, communicating, and working (American with disabilities Act 1990). Disability as such can be understood as the limitation that one has in relation with his/her physical or mental capabilities. In the light of such limitation, he/she has to depend on other for support in all the fundamental areas of life.

Disability can be related to conditions present with birth may affect functions later in life. Such conditions include disorders in single genes, chromosomal disorders, or mother's

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exposure to infections during pregnancy. Additionally, a disability can be associated with developmental conditions that become apparent during childhood or are related to an injury, associated with a long-standing condition, or a progressive illness (American with Disabilities Act, 1990).

Having a disabled child born into a family is a serious challenge because it can disrupt the normal routine in the family life. It can disrupt the marital relations between the couples, the healthy communication in the family and the positive family atmosphere. Hence, it is stated that this often leads to great distress and changes in the family life (Ozsenol, Isikhan, Unay, Aydin, Akin and Gokcay, 2003). It is a fact that a family with a disabled child has to face and undergo an extra weight of pressure and challenges to deal with life. As a result, this can disrupt a normal life in a family because of the extra care and resources that they have to put forth.

Parents of children with disability experience challenges which may lead them to make mistakes in upbringing of their children and which can give rise to learning difficulties and other problems. They need to be motivated to become involved in the education of their children. Parents play a greater role in the education of their children because they know their children better and they can give advice about individual behaviour and they can also contribute to the design and implementation of joint learning support strategies (Lewis and Doorlag, 2006). It is a tough task to look after a child let alone when a child is in need of special assistance. Parents as such are in dire needs of assistance themselves from various agencies or groups in order to successfully cater to the needs of a disabled child.

Zerk (2005) noted that parents begin to grapple with questions such as: What would become of the child? What do we do? What caused this? Or how would this affect our status in the society? They become limited in ideas of how to cope with a permanent disability, guilt of probable omissions that resulted to the situation, anxiety, and deflated ego tend to weaken them. This is an enormous challenge that no one finds easy. Thus, having a special needs child brings huge psychological, emotional, spiritual and physical traumas to parents resulting to a spectrum of reaction in a continuum (Taila, 2003).

According to Smith (2002) parents of children with disabilities experience greater stress and a large number of care giving challenges, such as health problems, greater feelings of restrictions and higher level of parental depression than parents of children without disabilities. Some families experience difficulties in financial assistance and inadequate support from the members of the family and communities. Families of children with special needs faced both the normal pressures and tensions of family life and in addition, adjustments to the presence of the child with the disability. Such families usually require assistance in order to reorganize their lives towards positive adaptation.

Having a disabled child, regardless of disability type, brings some certain difficulties into the family. These difficulties mainly include mental health, financial situation, educational background, lifestyle, relationships with the family and social environment, and the child's disability. There have been research studies pointed out that mother takes on a more active role and makes more efforts to solve all these difficulties, and the experiences and the expectation of the parents with a disabled child vary according to the mother and father (Donmez, Bayhan and Artan, 2000)

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Some of the challenges described by parents raising a disabled child included primary concerns relating to themes of physical symptoms, communication and interaction difficulties and behaviour problems (Hartley et al., 2005; Smith et al. 2006). There are also parents that once they realize that their child is mentally challenged they are confronted with many challenges and problems (Upadhyaya, 2008). Thus, having a child with a disability in the family is one of the major problems that can affect the total well being among members of the family.

Disability and its affect on parents:

According to Benson, (2012) the long-term care of a child with a chronic disability frequently affects various dominant areas in a parent's life (e.g marriage, career, relationships), which can lead to stress, and often affects the overall functioning of the family. In addition, parents work to balance their marriages with demand that accompany having a child with special health care needs. Because children with disabilities may require continuous medical support to meet their needs, a parent's career is then affected because of high rate of absences and reduced work hours.

Holden, et al., (2002) found that parents of children with mental health problems reported missing work or ignoring other activities because of their children's emotional or behavioural challenges.

According to Pritzlaff, (2011) depending on the child's ability to interact and communication with their 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 efficacy and competency.

According to Beresford, et al.,(2007), states that no matter how severe the special needs of the child is, the parents are inevitably affected in one way or the other. Most of the parents are affected emotionally. Parents often struggle with guilt; they feel as though they somehow caused the child to have disability, whether from genetic, alcohol use, stress or other logical or illogical reasons. This guilt can harm the parent's emotional health if it is not dealt with. In India, parents of disabled children face stress and it affects their health (Pal, et al., 2002). In a developing country like India, a disabled child is considered as a stressful experience and such situation is described as a burden (Rastogi, 1981).

According to Singhi, et al., (1990) the families of disabled children have great financial stress, poor social interaction and negative effect on their physical and mental health compared with that of families of non disabled children.

According to Quine and Paul, 1985; Roach et al., 1999; Valentine et al., 1998, states that parents of children with disabilities experience greater stress and a larger number of care giving challenges, such as more health problems, greater feelings of restriction, and high levels of parental depression than parents of non disabled children.

Statement of the Problem

Parents of children with disabling condition faced various challenges that are often not addressed as resources tend to be primarily child focused (Woodgate, Ateah, and Secco, 2008). The untold problems of parents are a concern that needs to be dealt with properly and effectively. Raising a child with disability causes significant financial stress. Current research

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has shown the percentage of families with both parent in work force is higher than those with only one parent working (Parish, Seltzer, Greenberg, and Floyd, 2004). However, in developing countries like India, the problems that parents are facing cannot be limited only within material mode of existence. Undeniably, parents with a disabled child face unlimited challenges and problems in all areas of life. A parent's with a disabled child can negatively affect the emotional, mental and physical health. Raising a child with disability requires strength and flexibility. Parents can find themselves overwhelmed by various medical, care giving and educational responsibilities.

As per the limited knowledge and information of the researcher, in North-East and Meghalaya there's no research related to the challenges faced by the parent of disabled children. There is a lack of concern among the general public to discuss about this particular issue due to lack of resources, information and knowledge. As noted earlier, the approach that has been undertaken so far in this area is of one sided, focussing only on the child with a disability especially in our context, India. Hence, the researcher finds it of an utmost important to deal with issues that have affected parents with a disabled child and their everyday life experienced.

Research Questions

- What are the various challenges faced by parents of disability?
- What are the affect of parents with a disability children?
- What are the facilities provided by the Government for disabled children?

Research Objectives

- To identify the challenges faced by parents of children with disability at Khulu Malang Memorial School for Special Needs, Thadlaboh Tyndowapung Jowai, West Jaintia Hills District.
- To examine the affect on parents of children with disability at Khulu Malang Memorial School for Special Needs, Thadlaboh Tyndowapung Jowai, West Jaintia Hills District.
- To identify the facilities provided by the Government for the disabled children at Khulu Malang Memorial School for Special Needs, Thadlaboh Tyndowapung Jowai, West Jaintia Hills District.

Operational Defination:

- Challenges – Are the different obstacle caused to the parents due to the disability of their kids to function normal or have a normal well-being.
- Parents – In this study are those people who are responsible for the disabled child.
- Disabled – Is the lack of ability to do something.
- Children- Words used to refer to young people who are younger than most of the people either in a room, a setup etc.
- Khulu Malang Memorial – Is a school built in the remembrance of the beloved (L) Mr. Khulu Malang.
- Special needs – It is referred to children with abnormalities who needs special catering in their day to day life.

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Significant of the Research Project

This study attempts to explore the life experienced of parents with a disabled child. Hence, it will shed some lights on the nature and the affect that parents are facing in dealing with the issue of disability. This study will also broaden the view and understanding of parents in relation with disability. Simultaneously, through an interaction with parents it will help to broaden the scope of our understanding about their plight and circumstances. In this way, it will help both the counsellor and counselee to tackle with the issue in a productive and meaningful ways.

RESEARCH METHODOLOGY

Area of the study

The area of study for this research is focused at Khulu Malang Memorial School for Special Needs, Thadlaboh Tyndowapung Jowai, West Jaintia Hills District.

Research Design

This study is an exploratory research design because the main aim of the studies is to explore and inquiry about the challenges faced by parents of disabled children and to explore the research question of the research study. It is a mixed method both qualitative and quantitative method. For qualitative it data, it was derived as an interview with the parents and for the quantitative the researcher used questionnaire.

Sampling Unit

- **Inclusion Criteria:** The researcher include the Executive Secretary i/c SELD of the KJP Synod Mihngi and the Headmaster of the school in order to help the researcher to know about the challenges faced by the parent of disabled children at Khulu Malang Memorial School for Special Needs, Thadlaboh Tyndowapung Jowai, West Jaintia Hills District.
- **Exclusion Criteria:** The researcher excluded the sister, brothers, aunty, uncle of the children, because the study focuses only on the parents.

Sample Size

In sampling size the researcher went to 20 household of disabled children, but those who study at Khulu Malang School of Special Needs at Thadlaboh Tyndowapung Jowai, West Jaintia Hills District.

Sampling Method

This study employed a convenient method because there is only one school for special needs or for the disabled children at West Jaintia Hills District.

Methods of Data Collection

For the purpose of this research, the researcher had used semi structured questionnaire.

Data Analysis: Thematic analysis and excel sheet

Thematic analysis is the process of identifying patterns or themes with qualitative data (Braun & Clarke, 2006). The patterns in the data that are important and use these themes to address the research or say something about an issue Braun & Clarke (2006), provide six-phase guide which is useful framework for conducting this analysis.

- Step 1: The data has been analyses by reading or listening to the recordings, that has been recorded during the interview and transcripts it into verbatim, then the researcher become familiar with the data.

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- Step 2: The researcher analyses the data by generate the initial codes after reading the transcripts and then the codes are captured something interesting and meaningful word.
- Step 3: After generate the initial codes, the researcher categorize the word that has appeared mostly and then the researcher gathered all the data that are applicable to each theme.
- Step 4: The researcher analyses the data by review, modify and develop for themes.
- Step 5: After reviewing are done the researcher then refining and generate the clear definitions for each themes.
- Step 6: After the researcher defined the main theme, it give the reports and then connecting the analysis back to the questions, objectives and journal article.

Ethical Consideration

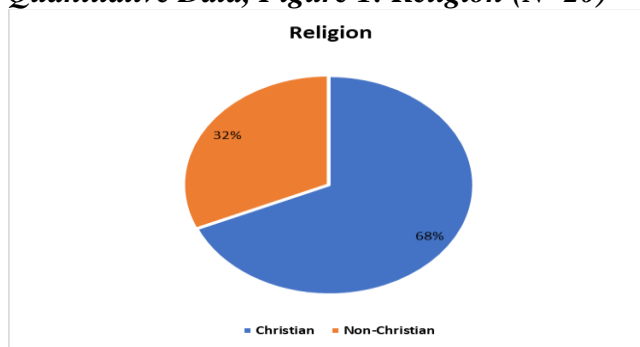
For the purpose of this research, Informed consent present before the participants. The informed consent form includes the information about the purpose of study, the procedure of the study and the statement of confidentiality which emphasizes that their identities will remain anonymous and every effort will be made by the researcher to preserve the confidentiality. It also mentions that the participation is voluntary and can be withdrawn at any point of time. It also state that the disguised extracts from the interview may be quoted in dissertation, presentation, published papers, etc. The participants were also asked to be honest and be accurate when answering the questions.

Findings

In this chapter, it represent the findings of the study at Khulu Malang Memorial school with special needs, Thadlaboh Tyndowapung Jowai, West Jaintia Hills Duistrict of Meghalaya. The researcher used questionnaire for collection of data. The researcher also employed semi structured questionnaire to collect data from parents of disabled children. In this chapter it shows that there are 20 respondents. A sample of 20 parents (n=19 female and n= 1 male) were participated in the research. There are 20 parents and 14 who belong to the religion Christian and 6 are Non-Christian. The occupations of the respondents are 32% labour, 21% housewife, 11% teacher and farmer, 10% cleaner, 5% peon and helper. In the qualitative data the results shows that parents faced various challenges like financial problems, anxious and time management. For the affects it shows that parents affected them like stressful events and psychological issues. However, in this chapter the following tables and figures explain more about the quantitative data of the responses by the respondents which the researcher has choose some of the questions.

The following tables show the findings of the data collection.

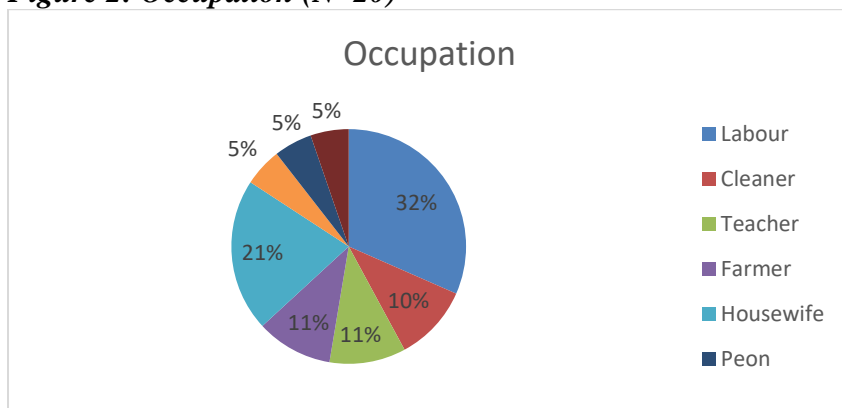
Quantitative Data, Figure 1: Religion (N=20)



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The figure 1 shows that 68% of the respondents are Christian and 32% of the respondents are Non Christians.

Figure 2: Occupation (N=20)



In the figure 2 the occupations of the respondents it shows that labour 32%, housewife 21%, farmer and teacher 11%, cleaner 10%, peon and helper 5%.

Table 3: Do you face difficulties in managing time? (N=20)

Response	Respondent	Percentage
a) Very much	10	50%
b) Sometimes	10	50%
c) Not really		
d) Never		
Total	20	100%

The table 3 it shows that respondents are facing difficulties in managing time it is seen than 50% of the respondents says very much and 50% says sometimes.

Table 4: Do you often feel stress related fatigue? (N=20)

Response	Respondent	Percentage
a) Yes	15	75%
b) No	5	25%
Total	20	100%

The table 4it shows that the respondents are feeling stress it is seen that 75% of the respondents are stress and 25% they're not having stress.

Table 5: Do you often upset at household/office or any work? (N=20)

Response	Respondent	Percentage
a) Always	4	20%
b) Sometimes	12	60%
c) Depending on my mood	1	5%
d) Never	3	15%
Total	20	100%

In the table 5 it shows that parents who often upset with household/office or any work it is seen that 60% of the respondents upset sometimes, 20% of the respondents who upset always, 15% of the respondents never upset with their works and 5% depending on their mood.

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Table 6: Does having a child who needs special attention affect your relationship with your family, friends, spouse? (N=20)

Response	Respondent	Percentage
a) Yes	10	50%
b) No	10	50%
Total	20	100%

In the table 6 it shows that 50% of the respondents affect the relationship with their family, friends and spouse, whereas 50% of the respondents does not affect them.

Table 7: Does having a child with special needs affect your thoughts and behaviour (N=20)

Response	Respondent	Percentage
a) Yes	14	70%
b) No	6	30%
Total	20	100%

In this table 7 shows that 70% of the respondents affect their thought and behaviour whereas 30% does not affect them.

Table 8: Do you get any scholarship or schemes from the State Government for your child? (N=20)

Response	Respondent	Percentage
a) Yes	17	85%
b) No	3	15%
Total	20	100%

In this table 8 it shows that 85% of the children from this school got scholarship whereas 15% did not get the scholarship which was provided by the Government.

Table 9: Do you think the scholarship or schemes of the Government are enough for the need of children with disability? (N=20)

Response	Respondent	Percentage
a) Yes	2	10%
b) No	18	90%
Total	20	100%

Table 9 shows that 90% of the respondents states that the schemes of the Government are not enough for the need of their child with disability and 10% of the respondents states that the schemes which provided by the Government is enough for the need of children with disability.

Table 10: Are you aware of any programme of the Government that provides for parents on coping disability children (N=20)

Response	Respondent	Percentage
a) Yes	7	35%
b) No	13	65%
Total	20	100%

From the table 10 it is seen 35% of the respondents aware the programmes that the Government provides for parents on coping disability children whereas 65% of the respondents does not aware of the programme that the Government provides for parents on coping disability children.

Qualitative Data: Challenges faced by parents of disabled children are:

In the qualitative data, there are 20 respondents who have been interviewed. The challenges faced by parents of disabled children are discussed below:

A. Financial Problem

Financial problem can be the major challenges for the parents of disabled because some of the parents cannot afford the medical cost because of its expensiveness. Some parents experience this in their life which can leads them to be affected emotionally and physically. Some of the respondents shared that they have financial problems and the following findings indicate such problem,

“Working as a labourer hhhmmmm....I faced a lot of problem especially to take my daughter to the doctor because the treatment is too expensive.” (mother/ February 2021)

Another respondent state that,

“Hhmmmm....When I knew that my son suffer from autism, I want to go to Mumbai for the treatment but I can't afford to pay the expenses for the flight, hospital and medicine bills because it is too expensive.”(mother/February 2021)

Another respondent state that,

“Hhmmmm.....We are working as farmer so we hardly take our son for medical checkup because it cost lots of money.” (father/ February 2021)

From the above following voices, it is clear that parents find it very hard to manage financially for their disabled child. As stated, it is also clear that for medical treatment regarding disability proves to be costly and this poses a big problem for families having disability children. Though parents/caregiver expresses their concern for a better treatment of their children yet it is without of their reach. Therefore, for such families it is important to inform them about schemes provided by the government and on the other hand the government needs to set up proper channels that can be easily access by the families.

B. Anxious

Another important factor that some parents faced is a deep concern and worried for their children about the future and care giving. The following are some of the concern being shared,

One respondents stated that,

“Hhmmmm.....I am worried every day of my life for the future of my daughter because there's no one to look after her when I die and my family also don't want to look after her because she's disabled”.(mother/February 2021)

Another respondent who had a horrible experienced stated that,

“Ahhhhh.....From the day my daughter was raped by her uncle, I was so worried for her when I go to work as she was alone at home”.(mother/February 2021)

Another respondents state that,

“Hhmmmm.....Even though my daughter was disabled but I accepted it, even though it was difficult to take care of her but I continue to bear the responsibility as a mother. However, when I think about her future I worried for her when she reach the stage of adolescence because she cannot speak and didn't understand if something bad happens for her”(mother/February 2021).

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These heart rending and painful revelations from respondents reflects the struggles and pain that parents/caregiver have to undergo every moment of their life. It is not easy to bear such a weight everyday thinking about the future of dear and near ones when the path seems dark and gloomy, and how much more when family members fails to see the pain and the struggle that one has to bear. As parent one is bound to give in to the pressure of such a weight and rob oneself of the joy of living daily. So, in such a dire circumstance one needs a constant support from every force available to them.

C. Time management

According to the data collected, time is another crucial factor that determines the prospect of most parents. Since, most of the parents have to earn their livelihood everyday, they find it very difficult to devote their time to their disabled children. Some respondent state that,

“Ahhhh.....As a labourer, I had so much difficulty in managing my time with my daughter as I always have to assist her in daily basic chores.”(mother/February 2021)

Another respondent state that,

“Ok hmmm....Being poor, I have to work as a house maid from morning till evening time. The nature of the job demands me to be at work the whole day, in this way I find it very difficult to be with my daughter all day as she is not able to take care of herself.”(mother/February 2021)

A disabled child needs a lot of care and attention from his/her parents in order to protect him/ her from various harm and injuries, this in turns demands a lot of time on their part. However, as the data indicate, most of the parents find it very difficult to manage their time in taking care of their disabled child. The job that they took does not allow for them to have such a time. This is indeed a serious issue especially among poor families who cannot afford to hire someone for help or send them to a care centre for some time.

Affects on parents of disabled children

A. Stressful Events

Being stressful can take a heavy toll over the body. It can lead to some unhealthy habits and can have a negative impact on the body. When it comes to parents with disabled child it is obvious that they will have to go through a lot of stress in their life. Since, having a disabled child is life-long endeavour, stress among such families can prolong over a long period of time. The followings are some of voices related with this particular issue.

Some respondent stated that,

“Hmmm....Sometimes I used to be in a lot of stress thinking about the expenses of a monthly checkup for my daughter because it costs a lot of money. This has disturb my normal life”(mother/February 2021)

Another respondent stated that,

“Hmmm.....I used to be stress out thinking about my daughter, thinking about the incident when she was raped, this has always disturb me as she didn't understanding anything when I left her at home alone to go for work”(mother/February 2021)

Another respondent stated that,

“Ahhhhh Ok....Stress out for my son because I used to think about his future how he would live without me”(mother/February 2021)

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From the above data, it is obvious that parent/caregiver of a disabled child had to go under a lot of stress in their everyday life. The expenses that they have to provide for their child keep on circulating in their mind and this has disrupted their normal life. The thought of a future life of their disabled child left them with bleak vision of what the future holds for them. As noted earlier, living in such a condition can cause a serious blow to their mental, social and physical well being.

B. Psychological Issues

Parents were emotional when they look to their children as they were disabled. Psychological issues here can be understood as a strong feeling of sadness, anger, fear, hatred and guilt.

Some respondents stated that,

“Hhmm....It really affects me emotionally seeing my son in pain, it is heartbreaking”.
(mother/February 2021)

Another respondent stated that,

“Ahhhhh.....Because my son was suffering cerebral palsy so it really affects me emotionally when I see my friend’s kid was normal” (mother/ February 2021)

Being sad about a certain situation is quite normal; however, if it take charge and control our life it can be hazardous for our total well being. Negative emotion if it persists for a longer period of time can rob a person from many good things of life. Sometime even our bad situation can help us learn about life in a meaningful ways. If negative emotions dominates our psychological makeup it can have an adverse impact on our decision and our view about the situation that were in. hence, it is important for parents of a disabled child to get constant emotional support in order to have an upward trajectory of life.

3. Facilities

Everyone needs help in one way or the other. Families of disabled children also need a proper facilities and help from outside sources such as government and NGOs. We cannot deny that, these mentioned groups have rendered their resources to the best of their ability. However, there is much room for improvement in order to cater to the needs of the people. the following are some of the concern shared by respondents in relation with this matter.

Most of the respondents stated that,

“We apply for scholarship from the school which the government provided for Rs 3000, however we received this only once in a year. This is not enough.” (parents of the respondents/February 2021)

Few of the respondents stated that

“We have applied for the same scholarship, but till now we have not received even one rupee.” (parents of the respondents/February 2021)

The condition and the plight of families with disabled children cannot be overlooked. As a government and other groups are trying to lend their support and helping hand to such families it is important to follow up of how their resources are utilized and whether they met the needs of the people. It is also important for the government to set up proper channel for people that those who are in need can access easily to facilities being provided.

DISCUSSION

In this chapter the results of this research are discussed in terms of similar reports drawn from other literature reviews. This discussion focuses on the three main objectives of the study drawn from primary data given by respondents using the tools of questionnaire and interview. In the present study, there are 20 respondents. There are 19 mothers and 1 father all together. The participants used both questionnaire and interview. In the figure 1 it shows that 68% of the respondents are Christian and 32% of the respondents are Non-Christians. In the figure 2 the occupations of the respondents it shows that labour 32%, housewife 21%, farmer and teacher 11%, cleaner 10%, peon and helper 5%. In table 3 it shows that respondents are facing difficulties in managing time it is seen that 50% of the respondents says very much and 50% says sometimes. From table 4 it shows that the respondents those who are feeling stress it is seen that 75% of the respondents are stress and 25% they're not having stress. In the table 5 it shows that parents who often upset with household/office or any work it is seen that 60% of the respondents upset sometimes, 20% of the respondents who upset always, 15% of the respondents never upset with their works and 5% depending on their mood. In the table 6 it shows that 50% of the respondents affect the relationship with their family, friends and spouse, whereas 50% of the respondents does not affect them.

In this table 7 shows that 70% of the respondents affect their thought and behavior whereas 30% does not affect them. In this table 8 it shows that 85% of the children from this school got scholarship whereas 15% did not get the scholarship which was provided by the Government. From table 9 it shows that 90% of the respondents states that the scholar or schemes of the Government are not enough for the need of their child with disability and 10% of the respondents states that the schemes which provided by the Government is enough for the need of children with disability. From the table 10 it is seen 35% of the respondents aware the programmed that the Government provides for parents on coping disability children whereas 65% of the respondents does not aware of the programmed that the Government provides for parents on coping disability children.

The study done by Goredema P.B, (2018). This research aims to explore the challenges of parents with disability national disabled persons organization. The researcher used qualitative and used interviews and focus group discussions to collect data. In this study the findings revealed that some parents are experiencing financial problems. Many parents are not employed due to serious condition of their children which need parent's attention. As a result some parents suffer from stress, depress and disorders.

According to study of Bahry S. N et al., (2019) it indicates that most of the parenting burden stems from difficulties with time allocation, treatment, equipment costs as well as the balance between paid employment and caring responsibilities and increasing level of stress. In this study the researchers used convenient sampling techniques and quantitative studies. Firstly, as the data indicates, there are various challenges faced by parents of disabled children. Most of the respondents expressed that they face a lot of problems in dealing with the situation around them. Since most of them are poor and have to struggle for their daily livelihood they find it very difficult to manage their expenses in order to meet the needs of their disabled child. Consequently, they have to spend a lot of hours working and less time with their disabled children. In such a mode of existence, it is difficult for them conduct their lives normally; hence, this poses as a big challenge for their daily existence. This challenge can be categorized into three factors, financial, time factors and anxious.

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These factors work hand in hand in the sense that if they satisfied one of the factors the other will come into play and seek for their attention. Thus it demands for a balance lifestyle in order to meet the challenge of these factors. However, it is not as easy as it sounds; this is a serious problem that has to be dealt with in a productive way.

Secondly, the data also indicates that parents of disabled children are constantly affected with stress and emotional breakdown because of their children's needs, low self-esteem and thinking about their children's future. According to Kelly A. 2019, in the survey she conducted parents reported of both positive and negative responses. The negative responses which she found were anxiety, stress, worry, feeling depressed or down, grief and loss. It also indicates that there was also jealousy of typical families, confusion, and fear for the future and concerns about the impact on the wider family. The practical and emotional factors overlapped and were bi-directional.

According to the study of Bahry S. N et al., (2019) it indicates that most of the parenting burden stems from difficulties with time allocation, treatment, equipment costs as well as the balance between paid employment and caring responsibilities and increasing level of stress. In this study the researchers used convenient sampling techniques and quantitative studies.

Indeed, disability in the families can have an adverse effect on the parent/caregiver. When one thinks of the future of their disabled child it is bound to lead them towards a gloomy path. Many of the respondents reported that they were worried about what would happen to their disabled son/daughter in the future and who will take care of them when they fail to exist. Such questions continue to linger on the mind of the parents, if this is not dealt with properly it can cause serious harm to their physical and psychological well-being.

Thirdly, the finding of the study also shows that there are challenges faced by the parents of disabled children in relation with facilities provided by the government. These families have no proper information or knowledge about such support provided by the government.

Hence, it is important for such families to have comprehensive information about the facilities provided by the government through awareness programmes or seminars. On the other hand, the data also indicates that there are families who received such grants in the form of cash (Rs. 3000 per year), however, this amount is not enough to meet the needs of a disabled child, e.g. like medical expenses.

According to the article of Nanjwan, J. D. & Akah, L.U. (2014) it indicates that the parents of disabled children facing a challenge with health disabilities and the role of stakeholders include: socio-economic challenges, availability of family intervention services, challenges of ignorance and mythological issues and that social pathological issues. The threats that lack of every childhood intervention services in the areas of parents' education, counseling programs, parents' professional collaboration and socio-economic empowerment, pose to parents were examined.

The general picture of parents with a disabled child is alarming indeed that demands for serious attention from everyone. These families are in need of constant support and help in order to move forward in life meaningfully and productively without getting stuck in the same plane of existence.

CONCLUSION

In this chapter shows the conclusion of findings both qualitative and quantitative studies. By looking at the findings and interpretation according to the objectives study, it can be said that there are challenges faced and affects by the parents of disabled children at Khulu Malang Memorial School with Special needs. The findings of objective one, two and three are using questionnaire and interview. In the findings the challenges faced problems by parents like financial, time management and anxious. Furthermore, in the findings of second objectives the affect by parents of disabled children at Khulu Malang Memorial School with Special Needs, marked the feeling of stressful events and psychological issues. The findings of third objectives the facilities provided by government to this school was a scholarship of Rs 3000 but most of the children however received this only once in a year. Whereas few of the children have applied for the same scholarship, but till now have not received even one rupee.

Therefore, in all the above statement it shows that parents need help and to understand them in the situations that they all experience, however, by creating seminar, awareness or workshop in the community, societies, school and counseling session with counselor will be beneficial.

Recommendation

- To collaborate with the Executive Secretary i/c of SELD Department of KJP Synod Mihngi, the Headmaster and Teachers in order to identify the challenges, the affect and the facilities in the school of Khulu Malang Memorial with Special Needs
- To create awareness, seminar in the Communities, localities, School with special needs about the mental illness in order to provide support for vulnerable parents.
- To strengthen and develop counseling session in communities, localities, schools with special needs in order to provide and support for parents who need help.
- The future researchers can proceed and explore more with the study by expanding Sample size and to more schools with special needs on the challenges faced the parents of disabled children.
- The future researchers should conduct the research in the society or community in order to get more findings and results.
- The Government or the NGOs should provide more facilities for the disabled children especially schemes and scholarship which they can afford for their needs.

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Conflict of Interest

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