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ASSESSMENT OF PHYSICALLY DISABLED CHILDREN'S FAMILY LIFE: THE CASE OF CLUBFOOT CHILDREN WITH SPECIAL REFERENCE TO BLACK LION HOSPITAL

A project proposal to be submitted to Indira Gandhi National Open University School of Social Sciences in Partial Fulfillment of the Requirements for the Degree of Master of Social work (MSW)

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1.0 Introduction

This chapter will contain introductory part of the entire study. It provides some insights about the ground and assumptions where the study is conducted. It starts with background of the study, statement of the problem, research questions, objectives of the study, and target population.

1.1Background of the Study

Disabilities exist everywhere in the world. They are of various kinds and have different effects on different persons in that some may be temporary or permanent, partial or total, fixed or changeable, have profound or no apparent effect on the working life of a person. They can be classified on the basis of their causes, nature, or other factors. Based on the cause or origin of the disability, it can be classified as: congenital or early childhood disability; war disability; industrial disability or occupational disease; accident in street, at home, at play; illness and disease (ILO, 1985: 5).

On the basis of clinical or nature, disability is classified as: orthopedic cases; blind; deaf; those with speech defects; those suffering from nervous disorders; the tuberculosis; paralyzed; and, the mentally retarded. Listed seven types of disability groups based on the "international classification of diseases and injuries": the visual [the blind and the weak sighted], the oral [the deaf and hard of hearing], the intellectual [mild, moderate and profound retardation], the motorical [neurological, musculo-skeletal and crippling, chronic health conditions], the lingual [oral and/or graphic], behavioral [emotional and social] and the multiple disabilities. Thus, this classification is made on the basis of the nature of the disabilities (Terusew, 1993: 69)

It is no secret that raising a child with disabilities can affect family life in many ways both positively and negatively. Research has shown that levels of parenting stress might be increased compared to families having children with typical development. Regarding the disability, there is always an impact in all life domains of the family (Dardas & Ahmad, 2014).

There are challenges that parents of children with autistic syndrome face in their social life as well as their work place. The families with autistic children tend to withdraw from activities that include social contact. Moreover, some parents seem to choose to quit their jobs in order to support their child together with the family members and professionals (Dardas & Ahmad, 2014).

In a study regarding the impact of having a sibling with an intellectual disability, the majority of parents also reported benefits to their other children such as: tolerance and acceptance of differences, caring and compassion, maturity, patience, assistance/support, appreciation of own life, and health. The study proved that there are some factors that have impact on the family life such as: personality of the child, type of disability, family style, mental health, attitude and parental well being (Mulroy, Robertson, et al., 2008).

When the condition is present from birth, the child's life and identity are shaped around the disability. In some ways, it may be easier for a child and his or her family to adjust to never having certain functional abilities than to a sudden loss of abilities later. Kingau (2018) mentioned in her studies that in Africa, the structural deformities are associated with stigma, which has a psychological and social effect on children, parents and caregivers. It is therefore imperative to understand the experiences of parents/ caregivers of children with clubfoot.

According to Save the Children's report of 2008, 11,317,000 children do not get basic health care in Ethiopia. UNICEF stated that PWDs, including children are less likely to receive medical care as compared to non-disabled individuals. Families face numerous challenges which included; long travelling distance, cost of treatment, travelling, poverty, stigmatization, lack of family support, and problem with abduction braces among others. The challenges facing parents/caregivers of children with clubfoot start after birth and are enormous.

Children with disabilities experience stigma from birth and are prone to exclusion, cover up, leaving behind, institutionalization and abuse. Families have hidden away children with disabilities, keeping them out of school and exclude from any opportunity to having

a role in their family (Wegayehu, 2004). The society negatively labels and ostracizes those with visible disabilities.

We know that children face challenges in their everyday life, and the family have difficulties caring for their disabled children. But, what does the family life of the disabled children look like? This study will aim to answer this question. It will focus on one of the health care institutions, Black Lion hospital, where physically disabled children get treatment; the study will particularly focus on the assessment of the family life of children with clubfoot disabilities. Regarding the family life of disabled children, conducted researches are insufficient specifically on the assessment of physically disabled children's family life in Ethiopia.

1.2 Statement of the problem

A number of researches are conducted on the different types of disabilities in Ethiopia. For example, research conducted on the nature and the difference of prejudice and discrimination against people with different types of disabilities (Tizita, 2014), a study done to examine the socio-economic challenges of women with disability in Hager Tibeb Maderaja Derijit, Addis Ababa (Eleni, 2016), assessment of disabled children attitudinal & behavioral changes at Menagesha Rehabilitation Center of Cheshire services- Ethiopia in West Shoa Zone (Tekle Mariam, 2013), experiences of persons with sensory disability and their vulnerability to HIV & AIDS (Etabezahu, 2013), the psychological, economical and social effects of Leprosy on affected women in A.A city administration (Rahel, 2016).

In general, it can be concluded that even though there have been studies on the family life of physically disabled children in developed and some developing nations, as per the knowledge of the researcher, there appears to be insufficient studies that give better attention on the family life of physically disabled children in Ethiopia, particularly those treated at the clubfoot clinic at Black Lion hospital. Therefore, I initiated this study to get more information to assess the family life of club foot children in Black Lion hospital. The study will attempt to answer the following research questions:

1.3 Research questions

As the focus of this study is already mentioned above, the study will try to answer the following basic research questions.

- 1. In what way does the disability of children affect the integrity of their families in Black Lion Hospital?
- 2. What are the challenges that the families face from having a child with clubfoot disability in Black Lion Hospital?
- 3. What are such challenges on the lives of families in Black Lion Hospital?
- 4. What are the possible suggestions and recommendations that are required reduce the challenges in the area?

1.4 Objectives of the Study

This study has general and specific objectives.

1.4.1 General Objective of the study

The general objective of this study is to assess the family life of physically disabled children with a special reference to club foot children at Black Lion hospital in Addis Ababa.

1.4.2 Specific Objectives of the Study

The specific objectives of this study are:-

- ➤ To identify if the disability of a family member affects the integrity of the family in Black Lion Hospital.
- > To find out the challenges that the families face from having children with clubfoot disabilities in Black Lion Hospital.
- ➤ To generate feasible suggestions and recommendations to concerned entities imitative to overcome the challenges

1.6 Significance of the study

This study is significant because it is hoping to:

- ➤ Contribute to knowledge regarding the family life of physically disabled children in Black Lion hospital through the voices of the parents/caregivers, which has not been given much attention in the scientific research,
- Raise awareness, regarding the challenges that the families face, to the public and the policy makers,
- Provide knowledge to the Ethiopian authorities regarding the needs of the families.

1.7 Target population

According to Zikmund et al. (2010) and Kothari (2004), a population refers to all items in any field of inquiry and is also known as the 'universe'. The study involves the families/caregivers of children coming to the Clubfoot service point at Black Lion Hospital. The study will be done at Black Lion Hospital. Hence, the actual population of the respondents is fifty (50 respondents).

1.8 Sampling Technique

According to Kothari (2004), non-probability sampling is that sampling procedure which does not afford any basis for estimating the probability that each item in the population has of being included in the sample. In this type of sampling, items for the sample are selected deliberately by the researcher; his choice concerning the items remains supreme. Therefore, this study will use purposive/judgmental sampling method.

1.8.1 Sample size of the Study

The sample for this study will be taken from Black Lion referral hospital which is one of the Clubfoot service points in Ethiopia. A sample size of 50 parents/caregivers that bring their children with clubfoot for treatment to this center will be used in the study. In addition, 10 families/caregivers will be included in the interview schedule.

1.9 Methods of Data Collection

Primary data will be collected from the respondents through questionnaire and interview of selected parents/caregivers. Both the questionnaire and interview will be pre- tested. Most of the interview to be conducted will contain close-ended questions. Therefore, the researcher will use questionnaire and interview to ensure collection of data from respondents and respondents will be free to give relevant information because they are assured of their anonymity (Mugenda and Mugenda, 2003).

1.10 Methods of Data Analysis

Descriptive statistics will be applied using SPSS for Windows Programme, and the analysis procedure include the following: The primary data on the family life of physically disabled children will be analyzed using descriptive and qualitative approaches that include frequency, average and the most commonly observed from the family life of physically disabled children. Interview data will be also charged for illustration.

1.11 Organization of the study

The report of the study is divided into five chapters:

Chapter One: Introduction: This chapter was divided into sub-sections, sets the background information to the research problem, statement of the problem, objectives of the study, research questions, significance of the study, scope of the study, limitation of the study, operational definitions of terms and organization of the study.

Chapter Two: Literature Review: This Chapter will focus on reviewing related literatures. It includes a brief main purpose of literature review such as related theories, theoretical reviews and empirical findings of the study which have a great help towards identification of the theories and ideas that explored such as data subsequently related to the study.

Chapter Three: Research Methodologies: The chapter will be divided into sub-sections such as research design and methods (data sources, target population, sampling techniques, data collection methods, and ethical consideration) and analysis of the study.

Chapter Four: Data Presentation, Analysis and Interpretation: It will be divided into sub-sections, namely, descriptive and qualitative analysis will be identified to the overall findings towards the family life of physically disabled children.

Chapter Five: Conclusions and Recommendations: Finally, this section will present a summary of findings, major conclusion and set recommendations on how to enhance the family life of physically disabled children through psychological treatment, in Black Lion hospital in general, suggestion are guidance for further research.

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