UNIVERSITY FOR DEVELOPMENT STUDIES, TAMALE

EFFECTS OF SUPPORT SERVICES ON PARENTS WITH INTELLECTUALLY DISABLED CHILDREN IN NKORANZA SOUTH MUNICIPALITY

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By

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THESIS SUBMITTED TO THE DEPARTMENT OF SOCIAL, POLITICAL AND HISTORICAL STUDIES, FACULTY OF INTEGRATED DEVELOPMENT STUDIES, TAMALE, UNIVERSITY FOR DEVELOPMENT STUDIES IN PARTIAL FULFILLMENT OF THE REQUIREMENT FOR THE AWARD OF MASTER OF PHILOSOPHY DEGREE IN SOCIAL ADMINISTRATION

MARCH 2019

DECLARATION

Student

I hereby declare that this thesis is the result of my own original work and that no part of it has been presented for another degree in this university or elsewhere:

Candidate’s Signature: ……………………………… Date……………….…………

Name: ………………………………………………………………………….

Supervisor

I hereby declare that the preparation and presentation of the thesis was supervised in accordance with the guidelines on supervision of thesis laid down by the University for Development Studies.

Principal Supervisor’s Signature: …………………………Date………………….

Name: ………..…………………………………………………………………

ABSTRACT

The care of children with intellectual disabilities is primarily undertaken by mothers who are considered the primary caregivers. This often predisposes them to a lot of physical, social and economic stress. For this reason, this study examines the effects of the available support services with the aim of making parents experiences visible to stakeholders. It will guide the design and provision of support services for them and their children. The study employed a case study design, purposive and snowballing sampling techniques in selecting sixteen (16) parents with intellectual disabled children and seven (7) key informants from support providers residing in Nkoranza south municipality in the Brong Ahafo Region. Semi-structured interviews and observation guided the data collection. The study found that families, government and non-governmental agencies provided parents with informational, emotional, financial, and social support in their quest for cure for their children. The support received contributed to parents reduced burden and hardship. Parents had emotional strength, hope and nourishment in dealing with provoking feeling of disappointment and heartbreak. In addition, parents had free time to engage in economic activities. Likewise, few parents who received financial support: livelihood support, cash transfers and disability grant had improved income status. Parent's improved social relation helped them to cope with their predicament in a better way. The support effected the ID children academic, social and vocational skills development. Hence, the study recommends that stakeholders should improve financial support, and equip the special schools with vocational training workshops that would enhance the social and vocational skills of the children.

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DEDICATION

This thesis is dedicated to God Almighty

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LIST OF ABBREVIATIONS

AAIDD	American Association of Intellectual and Developmental Disabilities
CRPD	Convention on the Rights of Persons with Disabilities
CBO'S	Community Based Organisations
DACF	District Assemblies Common Fund
DCF	Disability Common Fund
DSWCD	Department of Social welfare and community development
GES	Ghana Education Service
GFD	Ghana Federation of the Disabled
GSS	Ghana Statistical Service
GSPR	Ghana Social Protection Report
ICD	International Classification of Diseases
ID	Intellectual Disability
IQ	Intelligence Quotient
LEAP	Livelihoods Empowerment Against Poverty
MESW	Ministry of Employment and Social Welfare
MoH	Ministry of Health
MoGCSP	Ministry of Gender, Children and Social Protection
NCPD	National Council on Persons with Disability
NHIS	National Health Insurance Scheme
NGO's	Non-Governmental Organisations
PACID	Parent Association of Children with Intellectual Disability
PTA	Parent Teacher Association

PCC	Peace of Christ Community
PWD	Persons with Disability
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
WHO	World Health Organization

CHAPTER ONE

INTRODUCTION

1.0 Background of the Study

Children epitomize our future, every parent's yearning is to see her children grow up to be independent and responsible, but the birth of a child with a disability increases the prospect of provoking feelings of loss, helplessness and failure (Olsson and Hwang, 2008). The World Health Organization (WHO) (2010), defines "children with intellectual disabilities" as children with significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence) and to cope independently (impaired social functioning), which started before adulthood and has a lasting effect on development.

Similarly, the American Association on Intellectual and Developmental Disability (AAIDD) defines Intellectual disability as disability characterized by significant limitations both in intellectual functioning and in adaptive behaviour as expressed in conceptual, social and practical adaptive skills (AAIDD, 2008). The disability originates before age 18 years (Schalock, Luckasson, Shogren, Borthwick-Duffy, Bradley, Buntinx, & Yeager, 2007). Compared with normal children, children with Intellectual Disability (ID) are at a higher risk of having other health problems; the most prevalent are: epilepsy (22%), cerebral palsy (20%), anxiety disorders (17%), oppositional defiant disorder (12%), and autistic disorder (10%) (Oeseburg, Dijkstra, Groothoff, 2011).

The WHO expects that, ID should no longer be regarded as a disease but rather as a problem of the functioning of the whole person (WHO, 2010). More lately, the term

Intellectual Disabilities and learning disability has been suggested to replace "mental retardation, mental sub-normality and mental handicap" which are considered pejorative (WHO, 2010; Moeschler and, Nisbeft, 2011).

Children with disabilities are one of the most marginalized and excluded groups of children, experiencing widespread violations of their rights. Their plight is further compounded by poverty, social isolation, humanitarian emergencies, lack of services, support, hostile and inaccessible environment (UNICEF, 2013). According to World Disability Report (2010), globally, there is insufficient statistical information on children with ID and the services available to them. There have been many surveys to ascertain the prevalence of ID across the world with estimates ranging from 1% to 3% (Harris, 2006).

Over the years, many researchers have described the experiences of parenting a child with ID as stressful and challenging especially for mothers who are the primary caregivers of children in the family (Hill and Rose, 2009 Norizan and Shamsuddin, 2010; and Gona, Mungala-Odera, and Hartly, 2011). Parents face a great challenge with almost everything in the world. This includes: the desire to provide for their children in a safe environment that fosters good physical, social and emotional growth. The demands of everyday life are however, unknown and sometimes parents experience crisis in many forms. It is therefore not surprising that having a child with intellectual disabilities drive families into a chronic state of chaos.

In the past few decades, there has been some substantial amount of research on informal and formal support for persons with disabilities. Majority of the research on caregiving of children and adults with intellectual disabilities tend to highlight the 'burden' of caregiving on parents (Salovita, Italinna and Leinonen, 2003; Hassall, Rose, and McDonald, 2005; Kenny and McGilloway, 2007). Findings from such studies establish that, parents face significant challenges due to their parenting responsibilities and the difficulties they encounter when interacting with an often-unreceptive environment. Consequently, parents are at an increased risk for excessive levels of personal distress, which in turn adversely affects the wellbeing of the child and the entire family (Plant and Sanders, 2007).

Many studies have also attested to the nature of the experiences of disable people and their families. The dominant findings of these studies are that, disabled people and their families in any part of the world usually experience emotional, social, economic and political challenges in the form of stigmatization, discrimination, financial strain, lack of access to social, educational and health facilities, and marginalization (Beverly and Alvarez, 2003). The WHO postulates that, if parents, have a disabled child it may affect all aspects of family life, including decisions about work, education, family finances and social relation (WHO 2010). Due to the challenging behaviour displayed by most children with ID, parents hardly get free time for themselves, as all their time is spent caring for the child (Brown, Geider, Primrose, and Jokinen, 2011). Mother of ID children may be abandoned by their spouses and even the entire family because they have given birth to a child with ID (Aldersey, 2012). These challenges are more profound in third world countries, including Ghana. In Ghana, disability is seriously stigmatized due to the cultural beliefs attached to that condition (Avoke, 2002; Tinney, Chiodo, Haig and Wiredu, 2007; Kassah, 2008; Naami, 2012). Parents, especially mothers of children who have manifestation "abnormality" such as behavioral or physical disorders, may experience social rejection (Gona, Mung'ala-Odera, Newton and Hartley, 2011).

A study conducted on the experiences of families with ID children revealed that, the children receive labels, stigmatization and discrimination with various dehumanizing names whiles their parents become victims of isolation and mockery (Njenga, 2009; Nurullah, 2013). Evidence from other studies on perceptions about intellectual disability suggests that cultural and religious beliefs perpetuate these negative attitudes towards families with ID children (Avoke, 1997; Agbenyega, 2002). For instance a study in Kenya showed that, caregivers are either associated with evils spirits (jinnis), punishment from God, or witchcraft (Gona et al., 2011). With such notions of cultural ideology, disability in Ghana has also been attributed to witchcraft, sorcery, 'juju' or magic. Persons with Down's syndrome, in particular, are regarded as 'children' of the river gods (Avoke, 2001; Ocloo 2002; Anthony and Kwadade, 2006).

There are several types of support available for parents to assist them in their caring role, and these can be identified as either informal or formal (Tsai and Wang, 2009). Informal support has been identified as support received from family members or close friends (Australian Bureau of Statistics, 2005), whereas formal support is the one(s) provided by an organization or agency (Tsai and Wang, 2009). Additionally, other studies have revealed that social support, health-related quality of life, coping style and depression have direct and/ or indirect effects on caregiver burden (Choo, 2003; Gray, 2006; Carod-Artal, Mesquita, Ziomkowski, and Martinez-Martin, 2013). According to Ludlow, the appropriate general support from partners and members of the family, professionals and services contribute to reduce significantly the burden of caregivers (Ludlow 2012). Thus, there are numerous potential benefits in providing support, including increased positive effect and the feelings of satisfaction that can result from aiding a loved one (Lu and Argyle, 1992). Furthermore, some studies examining older adults have found that, support provision is associated with enhanced feelings of trust, intimacy, and a greater sense of purpose as well as decreases in psychological distress (Krause, Herzog and Baker, 1992; Liang, Krause and Bennet, 2001). In another study, Brown et al., (2003) concluded that providing tangible and emotional support resulted in reduced mortality among older adults. Even among parents of children with disabilities, they often perceive benefits in providing support and care for their child (Green, 2007).

From the foregoing, it is clear that many past studies have highlighted the potential benefits of support provision. However, some other research findings have noted that, in certain circumstances, offering support could ultimately be harmful for the provider (Silverstein, Chen and Holler, 1996; Brown, Nesse, Vinokur, Smith, 2003). Hence, researchers have posited that matching the support offered to the needs that support seekers communicate is essential to create a successful interaction for both support providers and recipients (Cutrona and Russell, 1990).

The bulk of research on support focuses on support provision among elderly adults or individuals in a caregiving situation (Krause, Herzog; Baker, 1992; Liang, Krause and Bennet, 2001). Little research has examined the outcomes of supporting the parents and its influences on the wellbeing of the intellectually disabled children. Understanding the consequences of providing support to chronically stressed individuals including parents of children with disabilities is important, as this support is crucial to minimizing potential burnout and declines in their well-being (Carretero 2009; Lovell, 2012).

Previous social support research has demonstrated the links between support, stress, and overall health and wellbeing (Lovell, Moss and Wetherell, 2012). Due to the stress parents with intellectually disabled children experience, adequate support is required to overcome the challenges the children pose for them. To help them manage these demands, parent's caregivers may rely on social support from friends and family (Lovell et al., 2012). United Nations Children Fund (UNICEF) also encourages countries to support families and caregivers of children with disabilities through professional training and financial assistance to improve on the quality of life for both parents and children (UNICEF, 2007). The functioning of a child should be seen not in isolation but in the context of the family and the social environment (World Disability Report, 2011).

Ironically, however, parents seem to get little or no support from family, community or professionals (Griffith and Hastings, 2013). In addition, health practitioners usually do not inform parents early about the diagnosis of their children and vital information required through counseling and education regarding what to expect, what to do, what services are available to them and where to get help, leaving them to explore the solutions by themselves (Tsai and Wang, 2009; Davies and Honeyman, 2013).

1.1 Problem Statement

Persons with Intellectual Disabilities report (2013) estimated that in Ghana, two to three percent of people have an ID, which is often characterised as persons having significantly below average Intelligent Quotient (IQ) below 70 and a deficit in two or more adaptive areas such as learning, communication, social skills, self-direction, self-care and, or work (Inclusion Ghana 2013). In view of the benefits that accrue to ID children and their parents, when they are provided with support, governments all over world have attempted to provide some intervention to support people with disabilities to alleviate their plight especially the vulnerable population within its area of jurisdiction (Social Security Administration, 2016; Olsson and Hwang, 2008).

Social protection, such as social transfers and social services for the most vulnerable and marginalized as a form of social support is gaining momentum as a development priority (Conway, 2000; Devereux, 2004;). Increased attention from governments, NGOs, academic institutes and donors is being accompanied by new calls to strengthen national governments to coordinate, regulate, and in some cases implement social protection programmes at scale (Miriam and Bette, 2008). According to *Ghana Social Protection Report* (GSPR) Social protection may play an important role in various aspects of children's care through its primary objective of reducing and mitigating poverty and its potential linkages to other services such as social work and child protection services (GSPR, 2014: 4). Also, the *Family for Every Child Report* (2013 and 2014), prepared by Inclusion Ghana, indicates that, the existence of support structures and access to basic services are imperative in addressing these other determinants of children's care (Inclusion Ghana, 2013; 2014).

Ghana has experienced some level of progress towards inclusion and promoting the rights of persons with disabilities. In June 2006, the Persons with Disability Act, 2006 (Act 715) was passed to guarantee Persons with Disabilities (PWDs) access to education, employment, transportation, public places, and free general and specialist medical care. In July 2012, Ghana ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), which can be interpreted as a major milestone in protecting and ensuring full an equal human rights as well as fundamental freedom for persons with disabilities (UN Enable, 2012). Currently, some persons with ID are registered via the Livelihoods Empowerment Against Poverty (LEAP) which is designed to reduce extreme poverty, hunger and starvation among the most severely disabled. The LEAP programme enables beneficiaries to register under the National Health Insurance Scheme (NHIS) for them to enjoy free health care. In addition, few NGOs and special schools have managed to get some of the District Offices of the National Health Insurance Authority (NHIA) via the Department of Social welfare office to register persons with ID in their organization (Inclusion Ghana, 2014).

Despite the Persons with Disability Act, as well as several other social protection intervention programmes, aimed at addressing the major disability concerns, not enough provisions and clear mechanism have been put in place to ensure that parents with ID children have access to the needed social interventions. Moreover, according to Ghana's Social Protection Report, understanding of the links between social protection and children's care is limited and little guidance is offered on ensuring that social protection promotes better care for children, through reducing family separation and enhancing the quality of caring relationships (Inclusion Ghana, 2014).

Information on the experiences of Ghanaian parents of children with intellectual disability needed to inform policy making is also scarce (Badu, 2016:21). Thus, there is much still unknown about how support services ultimately influence wellbeing of parents with intellectually disabled children in Ghana. This means that, in spite of the various attempts through policy instruments and other social inclusion interventions geared toward supporting parents and families with ID children, very little evidence exists to ascertain the nature, sources and effects of these interventions. As such it is often very difficult to assess the benefits the support services have had on families with ID children in Ghana.

In view of this evidence, this study examines the support services to parents of intellectually disabled children towards enhancing their well-being in the Nkoranza South Municipality.

1.2 Research Questions

Main research question

What is the nature and effects of support services available to parents of ID children in the Municipality?

Specific Questions:

- What are the sources of the support services to parents with ID children?
- Which kinds of support services are available to parents with ID children?
- How do support services provided affect parents with ID children?
- In what way(s) has the provided support services affected the lives of the ID children?

1.3 Main Research Objective

- This study aims at examining the support services available to parents of intellectually disabled children in the Municipality

Specific Objectives

- To examine the sources of the support services to parents with ID children.
- To identify the nature and type of support services to parents with ID children.
- To examine the effect of support services on the lives of parents with ID children.
- To describe the effect of support services on the lives of ID children

1.4 Significance of the Study

This study is envisaged to contribute to the paucity in research evidence regarding the nature, sources and effects of support services to Ghanaian parents with ID children. It hopes to generate findings that have relevant indications as to what type of support are appropriate for families with ID children and how these support services can be harnessed to provide optimum benefits for all. Findings generated from this study will also bring to light challenges faced by parents, children with ID and various state and non-state agencies responsible for providing support services, in their quest to deliver these services.

The main beneficiaries of this study include: social policy makers, Ministry of Gender, Children and Social Protection, and Department of Social Welfare who target families with intellectual disabilities children in the various social intervention programmes in the country. The findings of this study hopes to add to the literature on intellectual disability and parental care issues in Ghana and it will serve as a foundation for further studies. At the District level, the key findings of this research would help the Nkoranza South Municipal Assembly and any district around the research area to come out with exclusive byelaws on the treatment of the disabled child.

1.5 Scope of the Study

The study examines the support services available to parents of intellectually disabled children and how this is contributing to the wellbeing of both parents and children in Nkoranza South Municipality of The Brong Ahafo Region of Ghana. It focuses mainly on the perspective of parents with ID children as the primary receivers of support and other caregivers who may be recipients as well as the providers of support services.

1.6 Organization of the Study

The study is organized into five chapters. Chapter one provides the introduction, where the background of the study is outlined followed by the statement of the problem, research questions, objectives, significance of the study as well as the scope of the study. The second chapter presents a detailed review of literature, while the third and fourth chapter presents the methodology and discussion of findings. The final chapter summarizes the study, draws some conclusions and makes recommendations.

CHAPTER TWO

LITERATURE REVIEW

2.0 Introduction

This chapter presents a definition of some key concepts used in the course of this study. This is followed by an empirical review of literature on themes such as, sources of the support services to parents, the nature and type of support services to parents and the effect of support services on the lives of parents and ID children. Theoretically, the review also discusses the medical model and the social-ecological model of disability. The final part of the chapter presents a conceptual framework that supported the study.

2.1.0 Definitions of Key Terminologies

2.1.1 Child Disability

According to WHO (2011), children with disability refers to persons below the age of eighteen (18) who have any or those with health conditions such as cerebral palsy, spinal bifida, muscular dystrophy, traumatic spinal cord injury, down syndrome, and those with hearing, visual, physical, communication and intellectual impairments. Similarly, the term, 'children with disabilities' refer to children up to the age of 18 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 (UNICEF, 2013). ID is the most common developmental disorder (Boyle, Decoufle and Yeargin-Allsopp 1994).

2.1.2 Intellectual Disability (ID)

The term Intellectual Disability (ID) is increasingly being used instead of mental retardation. ID or mental retardation is defined as a condition of arrested or incomplete development of the mind, which is especially characterized by impairment of skills manifested during the developmental period, which contribute to the overall level of intelligence, i.e., cognitive, language, motor, and social abilities (WHO, 1992). The American Association on Intellectual and Developmental Disabilities (AAIDD) describes ID as characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills, this disability originates before age eighteen. In general, ID applies to the same individuals who were previously diagnosed with mental retardation in kind, level, type, duration and the need for services and supports. Every individual who is or was eligible for a diagnosis of mental retardation is eligible for a diagnosis of ID (Schalock et al., 2007).

2.1.3 Epidemiology of Intellectual Disability

According to the World Report on Disability over one billion people representing 15% of the world's population live with some form of disability, and of these, between 110 and 190 million have significant difficulties in functioning. The estimated number of children with disabilities between 0 and 18 years ranges between 93 million and 150 million, (WHO , 2011). There have been many studies to ascertain the prevalence of ID through the world with estimates ranging from 1% to 3% (Harris, 2006). Another meta-analysis, which considered studies published between 1980 and 2009 in European countries, found overall estimates ranging from 0.4% and 1.4% (Wittchen, Jacobi, & Rehm, 2011). Rates vary according to income; the highest prevalence occurs in low and middle income countries such as Ghana where rates are almost twice those in high-income countries (Maulik, Mascarenhas and Mathers 2011). In Ghana, disability rate is estimated to be 12.8 % (WHO, 2011). In addition, among the age group, 0–14 years, speech, (35.0%) and intellectual disabilities (25.5%) were the two leading types of disability (Ghana Statistical Service, 2013).

2.2 Common Causes of Intellectual Disability

An ID can be caused by any condition that impairs development of the brain before birth, during birth or in the childhood years. Several hundred causes have been discovered, but in about one-third of the persons affected, the cause remains unknown (The Arc, 2011). The known causes can be categorized as follows:

- *Genetic conditions* – These result from abnormalities in genes inherited from parents and errors when genes combine, or from other disorders of the genes caused during pregnancy (The Arc, 2011).
- *Problems during pregnancy* – The use of alcohol or drugs by the pregnant mother can cause ID. Other risks include malnutrition and illnesses such as rubella and syphilis of the mother during pregnancy, (The Arc, 2011).
- *Problems at birth* – Premature birth, low birth weight and difficulties in the birth process such as temporary oxygen deprivation or birth injuries may cause ID (The Arc, 2011).
- *Health/environmental problems* – Childhood diseases such as whooping cough, chicken pox, measles and meningitis as well as childhood injuries like a blow to the head or near drowning can cause ID. Lead, mercury and other environmental toxins can also cause ID (The Arc, 2011).
- *Poverty and cultural deprivation* – Children growing up in poverty are at a higher risk of malnutrition, childhood diseases, exposure to environmental health hazards and inadequate health care. These factors also increase the risk of ID (The Arc, 2011).

The severity of the ID can affect the ability of the person to live independently; therefore, it is important that proper diagnosis occurs to ensure the person receives appropriate support and a properly tailored treatment or intervention plan.

2.3 Manifestations and Subtypes

The manifestations of ID are mainly developmental delay in intellectual functioning and deficits in social adaptive functioning. According to the severity of the delay in intellectual functioning, deficits in social adaptive function and IQ, the psychiatric classifications describe four levels of severity (Ke, and Liu. 2012).

- First, the Profound ID is characterised by IQ level, which is usually below 20%; and accounts for 1% to 2% of all cases. These individuals cannot take care of themselves and have no language (Adams and Oliver, 2011).
- Secondly, the severe ID accounts for 3% to 4% of all cases and IQ is usually between 20% and 34%, they have difficulty pronouncing words and have a very limited vocabulary. Through considerable practice and time, they may gain basic self-help skills but still need support at school, home and in the community (Ke, and Liu. 2012).
- Thirdly, Moderate ID accounts for about 12% of all cases and their IQ level is usually between 35% and 49%. They are slow in meeting intellectual developmental milestones; their ability to learn and think logically is impaired but are able to communicate and look after themselves with some support (Ke, Liu. 2012).
- Lastly, Mild ID is characterised by slower Developmental delayed during their early life. It account for about 80% of all cases and IQ level is usually between 50% and 69%. However, they are able to communicate and learn basic skills. Their ability to use abstract

concepts, analyze and synthesize are impaired but can achieve reading and computing skills to grade three to six level (Ke, Liu. 2012).

Children with ID are at a higher risk of having other health problems. The most prevalent health conditions are Epilepsy, Cerebral Palsy, Anxiety Disorders, Oppositional Defiant Disorder, and Autistic Disorder (Oeseburg 2011).

2.4 Support Services Defined

Support is defined by Schalock et al., (2010) as “resources and strategies that aim to promote the development, education, interests, and personal well-being of an individual and that enhance human functioning” (Schalock et al., 2010: 175). The Convention on the Rights of Persons with Disabilities (CRPD) sees support and assistance not as ends in themselves but as means to preserving dignity and enabling individual autonomy and social inclusion (WHO 2011). In this study the phrase “support services” covers a range of interventions labeled elsewhere as “informal care”, “assistance and support ”, or “personal assistance”, but as part of a broad category which also includes advocacy, communication support, and other nontherapeutic interventions.

2.5 Parent of Intellectually Disabled Children

Parent refers to mothers, fathers, caregivers and other adults with responsibility for caring for a child, including families and friends, caregivers and those who look after children (Department for children Schools Families (DCSF), 2010). Pearlin, Mullan, Semple, and Skaff (1990) define caregiving as the “behavioral expression of one’s commitment to the well-being or protection of another person” (Pearlin, Mullan, Semple and Skaff, 1990: 583). Sociologists narrowly define caregivers as unpaid workers from family members, friends, and neighbors as well as individuals affiliated with religious institutions (Drentea, 2007). In this study parents refers to any person who plays a significant parenting role to a child; they may not necessarily be biologically related or even live with the child all the time but fulfills a significant portion of parenting and caregiving for the child.

2.6 Parenting and Caregiving to Intellectually Disabled Children: An Empirical Review

For nearly all parents, having children and caring for them is an experience with triumphs, joys, challenges and stresses (Resch, Mireles, Benz, Grenwelge, Peterson and Zhang, 2010). Although parents expect to provide caregiving during the growth of a child, the caregiver role takes on a new significance when parents are raising an ID child (Rain et al., 2005), especially since recent practice supports caring for these children in the home. It has been reported that the stress of mothering a child with Intellectual Disability (ID) affects all aspects of mothers life including mental, physical, emotional, social and economic (Davies & Honeyman, 2013; Gupta and Kaur, 2010).

The majority of studies to date have focused on mothers' experiences of parenthood and reactions to the child's ID, and fathers have sometimes been described as invisible or marginalised (MacDonald and Hastings, 2010b), as they did not become subjects of research until the 1980s (Blacher and Baker, 2002). However, as fathers appear to increase their involvement in the care of these children, fathers have become a new point of interest. This increase in father involvement may be due to the de-institutionalisation of individuals with disabilities (MacDonald and Hastings, 2010b) and changes in the social construct of the father's role in Western society (Tseng and Verklan, 2008).

Parental care for children with ID may drain the limited resources of families in terms of cost of treatment, training or therapies for the children. In addition, care for children with ID has reduced opportunity for parents to work to earn income because they are preoccupied with meeting the needs of the children. This further increases the poverty levels and frustration within families to the extent that parents may wish the children are dead (Norizan and Shamsuddin, 2010, Bourke-Taylor, Howie and Law, 2010; Edwardraj, Mumtaj, Prasad, Kuruvilla and Jacob, 2010). Arat-Kroc argued that, child care should not be a private responsibility of the mother and father, but that society and the state should at least share in the work, cost, and responsibility of raising children (2006: 86).

Globally, social support has been found to be one key resource for alleviating caregiver stress (Rodakowski, Skidmore, Rogers and Schulz, 2012). Support in this case refers to resources and strategies necessary to promote the development, education, interests and personal wellbeing of a person with intellectual disability. Support can be provided by a parent, friend, teacher, psychologist, doctor, or by any appropriate person or agency (AAIDD, 2008).

Male parents have been found to be important, if not essential, in their role as parents (Pleck, 2010). Men's parenting behaviour differs from women's, but differences are relatively small and the overlap is considerable between mothers and fathers (Lamb, 2010). When looking at what father's involvement implies, fathers' emphases appear to be on playing, nurturing, discipline, and deciding on services, while they appear to be less involved in activities concerning hygiene, dressing, feeding, teaching, and therapy, or taking children to service providers – tasks that tend to be the mother's main responsibilities (Simmerman, Blacher and Baker, 2001). Fathers of children displaying difficulties in terms of language development and behavioural problems tend to be less involved and express negative attitudes towards involvement in childcare (Bristol, Gallagher and Schopler, 1988). On the centrally, Carpenter and Towers (2008) found that British fathers wish to become more involved in childcare and request service providers and employers to be more accommodating and flexible to facilitate their involvement.

Available literature suggests that caring for children with disability and people who are severely dependent for whatever reason is time-consuming and exhausting (Bourke-Taylor et al., 2010; Hubert, 2011; Nurullah, 2013; Tsai and Wang, 2009). Mothers require extra energy and time to care for the special needs of an intellectually challenged child, which often cause them a lot of physical stress (Tsai and Wang, 2009). Parents with ID children are burdened with additional responsibility of giving medications, teaching the child skills (for performing activities of daily living) and doing physiotherapy (Nurullah, 2013).

The parent's experience of caring of ID may create a sense of guilt, shame, denial, anger and other negative emotions, which results in difficulty of accepting the child with ID (Nurullah, 2013). In Africa, a study in Kenya, reports that parents/caregivers often felt that their dreams and expectations regarding the prospects of the child had been crushed by the disability as most parents invest in their children with the hope that they will help them in their old age (Gona et al., 2011).

Parents caring for a child with disability may experience adverse effects on quality of life. Due to role demands parent experience decline in their physical and mental health (Brehaut et al., 2004; Cummins et al., 2007; Davis et al., 2010). In fact, many of these added stressors adversely affect parent/caregivers' overall health (Oelsfsen and Richardson, 2006), and can lead to depression (Hasting, Daley, Burns and Beck, 2006), marital conflict (Kersh, Hedvat, Hauser-Cram and Warfield, 2006), less effective parenting (Baker and Heller, 1996), and increased behavior problems in their children (Baker, McIntyre, Blacher, Crnic, Edelbrock and Low, 2003).

Although much research has not been done on the economic consequences of caring for a child with ID, there are studies that have examined direct costs of care, and the indirect effects on families' financial position. Families with ID children have reported of substantial costs incurred for treatment (Norizan and Shamsuddin, 2010; Bourke-Taylor, 2010). Recently, there has been an increasing interest in children with intellectual disability with researchers focusing on the experiences of mothers and social inclusion of children with intellectual disability (Njenga, 2009; Nurullah, 2013; Aarah-Bapuah, 2015). In studying caregivers of seriously disabled children and their relationship with the labour market, Borst (2010), noted that mothers of intellectually disabled children encounter financial problems in relation to the care giving process. McNally et al., (2013) reported of financial challenges among parents and caregivers of children with disabilities in the Moshi region of Tanzania in meeting necessities like food, clothes, nappies/diapers and shelter and high hospital and transport fees. Without proper access to resources, financial burdens arise, the child's health care needs continue to go unmet, and parents spend prolonged time searching for help (McManus et al., 2011).

The financial strain incurred by families of children with disabilities is likely due to increased expenses related to the child's needs as well as loss of employment or inability to work because of parenting responsibilities (Murphy et al., 2006; Worcester et al., 2008). In a study, mothers indicated that the demands of care giving might require that they leave their paid jobs in order to care for the child needs (John, 2012). Where the mother has no paid job, her chances of being employed are reduced because employers tend to weigh the number of working hours that will be sacrificed for care giving (McNally et al., 2013).

Socially, stigma of the disability and social segregation are reported to be the biggest challenge among mothers (Gona et al., 2011; McNally et al., 2013). Children with disabilities are killed by their families due to stereotypes by friends and the community (Baffoe, 2013). Mothers may be abandoned by their husbands due to affiliate stigma, while wealthy parents may be accused of sacrificing the child's intellectual capacity for wealth (Aldersey, 2012). In Africa, certain disabilities are considered as curses from the gods "evils spirits (jinnis), or witchcraft" (Avoke, 1997; Yankah 2009; Gona, Mungala-Odera, and Hartly, 2011). Mothers view the child as a burden or curse and blame God for giving them such burdens (John, 2012; Nurullah, 2013). Such undesirable beliefs serve as foundation for discrimination, stigmatization and isolation of disabled children and their families by society. Some parents hide their disabled child and do not openly seek help to avoid being stigmatized which leads to higher stress (Norizan and Shamsuddin, 2010).

In Ghana, as in many African societies, findings from a qualitative study on the experiences of parents of children with Intellectual Disabilities in the Ashanti Region of Ghana indicated that, parents as usual, experienced emotional stress, social stigma and financial hardship for taking care of children with ID (Badu, 2016). However the study was limited to a section of parents of children with intellectual disability in one region out of the ten regions in Ghana, The data was limited to the experiences of parents and did not include the views of service providers like doctors, special educators, social workers and broader stakeholders groups (Badu, 2016). Similarly key findings of a qualitative study titled *Experiences of Mothers with Intellectually Challenged Children in Tamale Metropolis of Ghana*, indicates that mothers experience difficulties in training the child, dealing with excessive care giving demands and challenging behaviours displayed by the child (Aarah-Bapuah, 2015).

As a means of coping, caregivers learn to deal with burden by using coping mechanisms that lower strain. Some of these mechanisms include support received from social and familial relationships, as well as from health care professionals (Cavallo et al., 2008), with focus on the needs of the child rather than on how parents are coping with the situation. Parents lean on their religious beliefs and perceive the child's disability as a gift from God and a trial of faith (Gona et al., 2011). Alternative method of coping employed by parents is by sharing experiences through self-help groups where mothers with ID children together with professionals meet together occasionally to share experiences and engage in related activities (Wang, 2009). Peer and Hillman, (2012a) speculated that having a positive outlook on life allows caregivers to see the benefit and joy of having a child and to avoid dwelling on the potential negative aspects of parenting an individual with an intellectual disability. They concluded that having an optimistic personal disposition helps parents to avoid associated caregiving stress by dwelling on benefit and joy of having a child Peer and Hillman, (2012b). Fathers of children with ID in the US use more distancing, escape-avoidance and positive reappraisal to cope with difficulties (Houser and Seligman, 1991). Indeed, caregiver burden experienced by parents raising ID children is linked to parents' well-being and can also lower the quality of care provided to the child (Emily and Nadine, 2006).

2.7 Sources of the Support Services

More generally, obvious sets of actors stand out as the sources and are involved in the development and growth of parental and family support services: international organizations, national and local civil society, including faith-based and community-oriented actors. Consideration also needs to be given to children and parents as important actors, and to professionals and employers (Daly et al., 2015). Evidence especially from the low and middle income countries suggest that international organizations are among the primary promoters of family support globally (Daly, et al., 2015). The relevant UN organizations play a major role with other international organizations; they frequently work in association with the national or local authorities and with national and international NGOs to inform decision-makers about policy options and in some cases to help introduce a new provision. International organizations may take the lead role as sponsors and financiers, policy innovators, ideas or programme 'translators', and/or service providers (Daly et al., 2015). For instance, the World Bank in particular promotes early childhood development as a policy and exerts a considerable influence on cash transfer policy in the global South (Daly et al., 2015).

Parental supports are also being promoted by various civil society organizations, international and national NGOs. The contribution of NGOs varies; they tend to play a significant role in introducing new thinking and provision. They may be prominent as providers especially in offering parental education and support (Daly et al., 2015). This may be for resource-related reasons, because government services are outsourced, or because many services are funded by donors and in this context NGOs are seen as the new "favored child" of official development agencies and proclaimed as a "magic bullet" to target and fix the problems that have befallen the development process (Edwards and Hulme, 1996). NGOs often provide community based and user-driven programmes to promote participation by people with disabilities in their communities (Holland, 2003 and Kandyomunda 2002). NGOs can collaborate with governments to deliver services for people with disabilities (Fisher 1997). Faith-based organizations may be important actors and often demonstrate leadership in regard to family support. In Africa for instance, the World Bank estimates that Faith Base Organisations (FBOs) provide approximately half of the continent's health and education services (Deneulin and Bano 2009).

According to Claire (2008), private for-profit suppliers of residential and community support services exist in most societies, where communities may involve peers, extended families, elders and community leaders as well as civil society and voluntary sector actors in parental support provision, their services are either contracted by government, or paid directly by the client (Claire, 2008). The 'community' sometimes also takes a provider role, especially in situations where local or state infrastructure is lacking and in many low-income and middle-income countries, consumer-led, government-delivered, or NGO-delivered community-based rehabilitation programmes are becoming a source of assistance and support for many people with disabilities and their families (WDR, 2011).

In Kenya, Gona et al., (2011), report that due to the demanding nature of care giving and the lack of rehabilitation services in the community, some mothers were able to get external support in the form of materials from Non-governmental Organizations (NGOs), charitable organizations and individuals who supported caregivers by providing wheelchairs and food. These organization and individual also sometimes assisted in paying treatment bills for children (Gona et al., 2011). Community-based rehabilitation organization, self-advocacy groups, or other collective networks can enable individuals with disabilities to identify their needs and lobby for service improvement (Charlton, 2000).

The state is most significant promoter and provider of parental support services. The state willingness or national 'readiness' or capacity exerts a major influence on what is introduced and how it functions. However, most assistance and support comes from family members or social networks. The state supply of formal services is generally underdeveloped, none profit organizations have limited coverage, and private markets rarely offer enough affordable support to meet the needs of people with disabilities, (World Bank, 2009, Fisher and Jing, 2008; and Saetermoe, Gomez, Bamaca and Gallardo, 2004). State funding of responsive formal support services is an important element of policies that enables the full participation of persons with disabilities in social and economic life. States also have an important role in setting standards, regulating, and providing services (World Bank, 2004; National Social Protection Strategy, 2008).

Ghana ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2012 (Human Rights Watch, 2012). According to UN CRC article 181, states must "render appropriate assistance to parents and legal guardians in the performance of their child-rearing responsibilities and shall ensure the development of institutions, facilities and services for the care of children." In response, Act 715 of Persons with Disability Act was enacted in June 2006. The act makes the following key provision for persons with disabilities (PWD): Education of a child with disability, facilities and equipment in educational institutions, free education and special schools, training of health professionals, periodic screening of children, establishment of assessment centers. Article 41 of the Persons with Disability Act, 2006 (Act 715) provides for the establishment of the National Council on Persons with Disability (NCPD), whose objective is to propose and evolve policies and strategies to enable persons with disability enter and participate in the mainstream of the national development process (NCPD/GFD, 2010).

Most countries that have developed support services have strong organizations of persons with disabilities and their families lobbying governments to reform policies on service delivery and to increase or at least maintain the resources allocated. In the United Kingdom, support from a disabled people's organization is an important influence on people with disabilities signing up for direct payment schemes (Riddell, 2005). Ghana Federation of the Disabled (GFD is a national umbrella of the disability organization, established in 1987 as a pressure group. GFD is recognized and accepted nationally and internationally as the face and voice of disability in Ghana. (NCPD/GFD, 2010)

The Disability Common Fund is a very important intervention among social protection policies to enable PWDs enter and participate in the mainstream of national development and also remove them out of poverty (NCPD, 2010). There exist guideline and principles governing the fund from the office of the Administration of District Assembly Common Fund (DACF). NCPD in collaboration with the GFD, District Assembly and Department of Social Welfare and Community Development ensure that both groups and individual PWDs who are not members of any Organisations of Persons with Disabilities (OPWDs); can access funding from the 2 % Disability Common Fund (DCF) (NCPD/GFD, 2010).

Yet, the disbursements of the funds to PWDs are district specific (NCPD, 2010; Sackey, 2009; SEND Ghana, 2010). According to SEND Ghana report on the District Assembly Common Fund (DACF), it was found that there was non-adherence to the guidelines for the utilization of the 2% DCF (SEND Ghana, 2010). However, the quality of the programme action and its significant influence on PWDs lives is dependent on the process of disbursement and management to its usage by beneficiaries (GFD, 2010).

The special schools are source of support to children with special needs. They have active education and training programmes that cater for those whose conduct and behaviour problems seem to require a more controlled environment. Research offers strong support for teaching students with severe disabilities both in academic content and functional life skills using systematic instruction writers (Browder and Spooner, 2011; Kennedy and Horn, 2004). In addition, strong evidence exists for teaching taxonomy, social and communication skills and providing positive behavioral support through Individual Education Programme (IEP) (Hunt and Marshall, 1999). The taxonomy is structured around five domains that represent the person as he or she lives, works, plays and moves through the community. According to Department for Education (1994) in Britain, the IEP plan aims at helping teachers to develop a clear and precise framework for the education of children with special educational needs that is also accessible to parents. According to Kyriacou (1986), teaching and learning materials are inevitable tools in the area of teaching and learning. Stones (1992) further found that materials and equipment sustain the interest of children in the classroom and keep them very active.

The salience of the extended family system can serve as a vital source of support for mothers caring for intellectually challenged children (Aldersey, 2012). They mainly provide emotional and physical support to mothers in the form of foodstuff and clothing and help in protecting the child from being beaten or harmed by other children (Aarah-Bapuah (2015). Studies have shown varied reactions from extended families with only few mothers getting extended family support (Anum, 2011; Edwardraj et al., 2010; John, 2012). Other studies have reported a lack of support from family, friends and neighbours. This shows that people relate differently to children with intellectual disabilities as well as their mothers based on their cultural perceptions. Some cultures characterize people with intellectual disability as bad omen labeling them with derogatory terms. However, some cultures are very receptive and mothers find their neighbours to be very supportive (Aldersey, 2012). The literature on support from networks acknowledges that, support from immediate families and friends are essential to assist parents who have a child with disabilities (Howie-Davies and McKenzie (2007). Siblings (especially female siblings) sometimes assumed responsibility of protecting and caring for their sibling with ID (Dyson, 2010; John, 2012). What is however not known is the extent to which siblings of ID children support their parents in caregiving.

2.8 The Nature of Support Services to Parents with Intellectually Disabled Children

Globally, parental support is growing in volume and reach, leading to innovation in forms of provision. Again, one finds wide variation and so it is not easy to decide on how best to classify the services involved. Supports are resources and strategies necessary to promote the development, education, interests, and personal well-being of a person with intellectual disability, supports can be provided by a parent, friend, teacher, psychologist, doctor, or by any appropriate person or agency (AAIDD 2011). There are several supports available for caregivers to assist them in their caring role, and can be identified as either informal or formal (Tsai and Wang, 2009). Informal support has been identified as support received from family members or close friends (ABS, 2005), whereas formal support is provided by an organisation or agency (Tsai and Wang, 2009). The types of supports available for parents/caregivers can be grouped into three broad areas: informational, emotional, and practical assistance (Tsai and Wang, 2009). Similarly, five different types of social support have been identified in the literature: network, esteem, informational, tangible, and emotional support (Cutrona and Russell, 1990).

2.8.1 *Informational Support*

Informational support assists the caregiver in their caring role, by providing knowledge, education or advice in regards to the caregiver's situation (Tsai and Wang, 2009). Similarly, Cutrona, (1996) postulate that Informational support involves offering information about a topic of concern with the Intention of providing assistance. Provision of informational support can be formal and informal. Formal information provision can be delivered via telephone, face-to-face, through the internet (Leonard et al., 2004), or via educational workshops. Informal informational support can be provided in the form of advice from friends and family (Shin and McDonaugh, 2008).

2.8.2 Emotional support

Emotional assistance can aid in assisting the caregiver emotionally and psychologically, by alleviating psychological and emotional stress (Shin and McDonaugh, 2008). Likewise, Cutrona, (1996) reported that emotional support has received the most empirical attention and occurs when an individual receives expressions of caring, love, and concern. It can be formally provided in the structure of support groups and counseling, and informally provided by friends and family by somebody who will listen and provide encouragement to the caregiver (Tsai and Wang, 2009).

2.8.3 Practical Support

Practical support can be in the form of respite and in-home assistance (Tsai and Wang, 2009). Respite is a service provided to the care recipient, which allows the caregiver to have some free time to engage in other activities besides the caring role (Strunk, 2010). In-home assistance is a service provided either by professionals or by family members, where the care-recipients are assisted with tailored services in their own home (Forde, Lane, McCloskey, McManus, and Tierney, 2004). These services can be in the form of tangible support which occurs when someone provides material goods or assistance to aid another (Cutrona, 1996). This could be equipment provision, leisure activities and assistance with activities of daily living for the care recipient (Forde et al., 2004). Evidence from a study shows that respite improves the parent-child relationship and reduces parental stress (Strunk, 2010).

2.8.4 Network Support

Network support is characterized by actions that help a person feel connected to a larger social group. Network support can be in the form of esteem support. Esteem support focuses on sharing feelings that validate the other person and boost their self-concept. Network support may include home visiting programs, parenting groups, center-based programmess and shared parenting models (Anderson and Lakin, 1998).

The work of Sloper (1988), uncovered some models of support service for parents of disabled children and these are; key worker model, parent counseling model, parent partnership model and other services. Provision of ‘key workers’ or ‘care coordinators’ working across health, education and social services has often been recommended in policy guidance. However, research continues to show that less than a third of families have a key worker (Glendinning, 1986; Sloper and Turner, 1992). Less attention has been devoted to understanding the qualities and types of supportive relationships that parents in comparable situations can provide each other.

The Parent-to-parent mentorship can take many forms, including one-on-one mentorship, community-based parent networks, technology-enabled parent networks, and peer support groups (Melbourne 2013). Technology-enabled formats such as internet chat rooms and computer-mediated support groups are increasingly being use as ‘virtual mentorship”. Konrad (2007) proposes that access to a confiding and nurturing relationship through a one-on-one connection can be a bridging experience for parents with a newly diagnosed child.

2.8.5 Financial Support

Financial assistance can be provided by the government, to help parents with the potentially increased costs of providing care for an individual with a disability. However,3 most payments are means tested, so not all caregivers/ parents are eligible (ABS, 2005; Redmond and Richardson, 2003). Literature reveals that in Ghana financial support is often in the form of social protection that targets parents with disabled children. One of the prominent social intervention programmes that seek to promote the well-being of children in Ghana is the Livelihood Empowerment Against Poverty (LEAP) cash transfer programme. The LEAP was developed by the Government of Ghana as one of its flagship programmes of the National Social Protection Strategy. It aims at empowering extremely poor, disadvantaged and vulnerable populations including children with disability in the country. The programme was initiated by the Ministry of Employment and Social Welfare (MESW) in 2008 and the implementation is done through the Department of Social welfare and community development (DSD), (Ministry of Employment and Social Welfare (MOESW) (2012). Government has increased the monthly stipend to beneficiaries. Currently, a single beneficiary takes GHC64.00, two beneficiaries in a household are entitled to GHC76.00 whiles three beneficiaries take GHC88.00 and four and above people are entitled to GHC106.00 (Ghana News Agency 2017).

LEAP is seen as a compliment to the governments existing social protection initiatives including among others such as Ghana School Feeding Programme and the National Health Insurance, which are in the study, does not have any specific focus for disabled children, but rather for children in general. Additionally, the Disability Common Fund (DCF) is one of such programmes in Ghana to help integrate disabled Ghanaians into mainstream society. In 2005, the Government of Ghana saw the need to establish the Disability Common Fund programme to respond to the needs of PWDs in the Ghanaian economy. Persons with disability are allocated 2% of the District Assemblies Common Fund (DACF), allocated to each metropolitan, municipal or district assembly (*NCPD/GFD, 2010*).

2.9 Effect of Support Services on Parents and Intellectually Disability Children

Parents, especially mother caregivers in general, rely on the availability of support systems as valuable resources to help them perform their role effectively. As shown in some quantitative studies, mothers with greater level of social support experience less amount of stress (Hill and Rose, 2009; Olsson and Hwang, 2008). In studying the relationship between caregivers strain and social support among mothers of children with ID in Taiwan, Tsai and Wang (2009) established that the higher the social support the lower the level of strain felt by mothers. They also found that emotional support received the highest score and informational support received the lowest score.

One study found that, among parents providing care for a child with autism those with greater perceptions of support experienced lower levels of psychological distress and fewer physical health complaints than caregivers experiencing lower levels of perceived support (Lovell, Moss, and Wetherell, 2012). Study shows that, if parents have improved Quality of Life, mental health and wellbeing, it is also possible that the benefits will be transferred to their children (Majnemer, Shevell, Rosenbaum, Law, and Poulin, 2007). Another study involving mothers of adult children with intellectual disabilities found that increases in perceived emotional support were significantly associated with psychological well-being (Hong, Seltzer and Krauss, 2001). However, most of the studies are quantitative in nature and were evaluated against standard quality assessment criteria. What has not been studied extensively is the extent at which parents subjectively appraise the effects of support on their lives and their children.

Evaluations of parent-to-parent support services have generally found that they serve as positive and preferred information for families of children with disabilities and chronic illnesses (Konrad, 2007). Parent-to-parent connection has also been shown to positively affect the physical and emotional wellbeing of both parents and children (Turnball, Blue-Banning, Turbiville and Park, 1999). Moreover, evidence suggests that peer-facilitated support groups offer a viable and acceptable outlet for parents to confide feelings and fears that otherwise would have remained silent (Foreman, Willis and Goodenough, 2005).

These parent one-on-one relationships can be formed formally – for example, by way of professional introduction – or informally – for example, when waiting for a medical appointment. Evidence suggests that the potential for positive adaptation to a child's disability or illness is increased when parents have a confidant who understands the private aspects of their experience. It further found that having someone who can share tested resources increases the likelihood that parents would successfully manage the practical aspects of their child's special needs (Jessop, Reissman and Stein, 1988).

A study by Keetie and Helen *researching the linkages between social protection and children's care in Ghana focusing on LEAP and its* effects *on child wellbeing, care and family cohesion* in the Central Region shows that, LEAP plays a positive role in improving child wellbeing and quality of care (Ghana Social Protection Report, (GSPR) 2014)**.** Findings of the study point towards positive effects regarding both material and non-material aspects of wellbeing and care for children. Cash transfers supported caregivers in purchasing food, clothing and other basic needs. It was also used to cover educational expenses, including school fees, meals, uniforms and books. The link to the NHIS has helped meeting costs related to health care, particularly for children (GSPR 2014). However, the report indicated limited sensitization on spending of cash for children's benefit or for promoting children's care, and misuse of money intended to improve household living conditions, and livelihoods. In addition, payment delays, arrears and large family sizes undermine the potential impact of LEAP on children (Ghana Social Protection Report, 2014**).** Similarly, Olsson and Hwang (2008) indicated that in Sweden, there are free services available to the vulnerable groups and in addition, most parents received a monthly grant to compensate for expenses and reduced income caused by caregiving demands. However, Villanger (2008) argue that cash transfer programmes in Africa usually covered few beneficiaries in a group.

In Ghana, special education for children with mental retardation was made legal through the Education Act of1961 and Persons with Disability Act 715, 2006, advocate education for all children. Scheerenberger (1983) postulates that special schools are the most appropriate for the mentally retarded because they have active education and training programmes. Hallahan and Kauffinan (1994) assert that the functioning of virtually all people with mental retardation can be improved and that those with mild and moderate conditions can improve their social skills and competence to the point that they are no longer classified as disabled when given the right placement and relevant programmes. As a result of the potency of the programme towards social skills development, the individuals with mild and moderate mental retardation graduate and find themselves functional in their communities contributing to their development (Stainback and Stainback, 1996; Lewis and Doorlag, 1995).

Assessment of social skills should be done under various contexts in order to establish a reliable performance level of the child (Hallahan and Kauffinan, 1994). This therefore calls for the critical observation of the child's behaviour in the classroom, on the playing field, among his peers and at home (Mandel and Fiscus, 1981). These informal measures, however, do not use standardised procedures. They are less structured and there is some amount of subjectivity in the administration, scoring and interpretation processes (Salvia and Ysseldyke, 1995). Gyimah (2000) mentions that these strategies include information gathered through observations of everyday behaviour of the student and interviews from parents and people who have known the child.

Research reported that, children who attend high quality programmess gain intellectual, social, and emotional competence, do better academically, and lead more productive adult lives (The Washington State Professional Development Consortium, 2010). However, the characteristics of the child also influenced the parent's perception and description as some children especially those with Down syndrome are generally known to be sociable and fun to be with (Grein and Glidden, 2014). Kaplan (1996) indicates that one important aspect of schooling is promoting social integration. Peers are powerful models in language, behaviour and social skills. Children with mental retardation benefit when exposed to the usual peer interactions that takes place in regular classrooms.

Hunt and Marshall (1999) emphasize that the teacher of the mentally retarded should use community-based instruction which involves teaching a skill in the environment in which it will be used. If children will be able to use money in purchasing items and understand the concept of change, they should learn it in the context of buying and selling in a store, learning how to use public transportation should involve actually doing it. Moreover, Mechling (2011) reviewed studies using portable electronic devices (PDA) to teach students with moderate intellectual disabilities and autism spectrum disorders. PDAs showed promise for teaching the multistep skills needed for daily living, transitioning between tasks, and time/task management.

Special teachers play a dual role; they are educators and parents. They also emphasise that special teachers should endeavor to establish collaborative links with the parents to promote learning of social skills and others at home and in school (Alderman 1990; Mercer and Mercer 1998)

Parenting a Child with ID in Ireland

The human rights of those with physical and mental disabilities are enshrined in the UN Convention on the Rights of Persons with Disabilities (CRPD) (UNCRPD 2006). United Nations Children Fund (UNICEF) also encourages countries to support families and caregivers of children with disabilities through professional training and financial assistance to improve on the quality of life for both parents and children (UNICEF, 2007). Ireland has a number of policy and Supports structures in place within its health, social care, and welfare system to support informal caregivers (Department of Health (DoH) (2012a). In Ireland, financial supports are available to families caring for a person in need of full-time care. The Department of Social Protection (DSP) offers a Carer's Allowance to eligible caregivers over the age of 18 years. Several support organisations have been established to support parents and caregivers in Ireland. Family Caregivers Ireland (FCI) (formerly the Caregivers' Association and Caring for Caregivers) is a national voluntary organisation that offers supports to family caregivers who provide care in the home. Such supports include a Free phone Care Line, home respite services, advocacy, information, and training (National Disability Authority Research Promotion Scheme (NDARPS) 2016).

A recent Irish study employed a mixed methods research design involving an anonymous postal survey of 600 family caregivers of people with intellectual disability, followed by one-to-one, in-depth telephone interviews with compound caregivers. The study examined the experiences of caregivers who were in receipt of a Carer's Allowance for the care of a relative with intellectual disability (Lafferty O'Sullivan, O'Mahoney, Taggart, Bavel 2016, and Brennan, Murphy, McCallion, Griffiths and McCarron, 2016). Findings revealed that, a third of caregiver's respondents reported having poor or fair health. Two thirds of the respondents reported that their own general health was good, very good, or excellent, however overall, respondents' self-reported health and wellbeing was poorer when compared to national data on caregivers (Lafferty et al., 2016: Central Statistics Office (CSO) 2012a). The study further found that majority of the respondents scored high in social connectedness. Caregivers generally experienced a strong sense of belonging and feelings of being connected to their friends and family members around them and to others in the society. These imply that the family caregivers who participated in the survey were relatively resilient. This may be attributable to a number of factors, including the fact that the majority of respondents had good self-reported health and high levels of social connectedness (Lafferty et al., 2016). Interventions aimed at enhancing resilience among parents of children with intellectual disability may not only benefit mothers and fathers, but may also benefit the child with intellectual disability. (Bekhet, Johnson and Zauszniewski, (2012)

The study further indicated that families availed from a range of services. Apart from Carer's Allowance, A day centre/school/college was deemed the second most helpful source of support (Lafferty et al., 2016). Across Ireland, day centres are the most commonly available services to families and people with intellectual disability (Barron, McConkey & Mulvany, 2006). Other recent Irish study comprising interviews and focus groups with a total of 17 family caregivers of people with intellectual disability also echoed that day-to-day services for people with intellectual disability, such as day services, workshops, and training centres, were ‘perceived by family caregivers to play an integral role in maintaining family caregiving capacity (Brennan, Murphy, McCallion, Griffiths, and McCarron, 2016). However, there were also unmet needs such as dietician services, home-based respite services, and occupational therapy, psychological / counselling services, sensory therapy (Lafferty et al., 2016). Also findings are based on data collected from caregivers who received a welfare payment for the full-time care of a relative with intellectual disability, and therefore the findings cannot be generalised to Africa where parent’s caregivers combined caregiving with full-time employment without any welfare payment, or Allowance. In addition, the reliance was based on caregivers self-reports, and therefore the data may be subject to increased levels of response bias.

Parenting a Child with ID in Pakistan

A qualitative Case Study of Khyber Pakhtunkhwa in Pakistan which employed In-depth Interview for 12 parents (6 from nuclear and 6 from joint family) and 28 parents for 4 Focus Group Discussions (FGD) were selected purposively from the official list of 3 Centers (Shakeel and Johar *2014*). The study explored the views and experiences of parents about their children with intellectual disability in joint and nuclear family structure, and the efficacy of services rendered by different Government-run-centers in reducing the miseries of parents. Finding of the study revealed that, parents belonging to nuclear family structure face various problems like social exclusion, strained spousal relation and extra fatigue for working mothers due to their full time involvement with their children with intellectual disability. However, parents in joint family were relaxed due to family support in child care and house hold activities (Shakeel and Johar, 2014). The study further observed that Institutional support was found significant among parents in releasing extra pressure of child care. Parents were happy due to the child's participation in the school for getting breathing space for managing other household activities. Therefore, the study concluded that Institutional and family support to parents in child care can reduce extra burden of child care and make them socially included (Shakeel and Johar 2014). However, the data of the study were limited to the experiences of parents and did not include the views of service providers like doctors, special educators, social workers and broader stakeholder groups. In terms of credibility, the studies did not demonstrate that there had been any discussion of the analysis with other researchers (an aspect that is usually undertaken to ensure plausibility and facilitate reflexivity), nor had they triangulated themes with their participants or with other sources of data for further validation

Parenting a Child with ID in Sweden

From a global point of view, many children with ID and their families are disadvantaged in terms of socio-economic status (Emerson et al., 2009; World Health Organisation, 2008). Since the 1980s, a pervasive reform of the care for individuals with ID has been carried out in Sweden (The National Board for Health and Welfare, 2009). Just like in many other Western countries, children and adults were moved from living in institutions to growing up in families (biological or foster families) and integrated in the community with support. In this context, Swedish families of children with ID served as an interesting example for researchers.

Swedish social welfare system attempts to compensate for the economic hardship. Sweden has relatively generous regulations and support available for all parents in terms of parental leave and parents' allowance, and families of children with ID are often entitled to additional support. Most individuals with ID in Sweden receive some support in accordance with the special civil rights law – the Act Concerning Support and Service for Persons with Certain Functional Impairments. About 36,000 persons with intellectual disabilities (about 0.4% of the population) receive support, and more than 17,000 of these are children and youth (The National Board for Health and Welfare, 2009). Families of children with ID can apply for economic compensation for the increased economic burden such as loss of income and the extra expenses due to the requirements of the child with disabilities (RiksFörsäkringsVerket (RFV), 2002).

Children with ID may attend preschool through the ordinary childcare services.

When they reach school age, most children with ID attend special school for children with learning disabilities – an integrated part of the ordinary school system. In order to allow parents of children with severe disabilities time off, there is short-term accommodation for their children and also the possibility to access support in their homes. Children who are diagnosed with ID and their families receive counselling, support and treatment by local habilitation teams in addition to the support provided by the regular national health services (The National Board for Health and Welfare, 2009).

Despite the seemingly unique possibilities of Swedish families of children with ID to receive healthcare and social and economic assistance, many parents talk of the great difficulties in gaining access to appropriate support (Socialstyrelsen, 2005). Parents explain that they struggle to get access to knowledge about their rights to receive support, and some families experience that only when the family is in a situation of crisis the authorities provided the appropriate information and support (Boström, 2012). To coordinate and apply for support is highly time-consuming for families, tasks that are added to a situation that is already stressful.

In a research Study of Swedish parents of typically developing children, Elvin- Nowak (Elvin-Novak, 2001; 2005) found the experiences of mothers and fathers to be quite different in some aspects. An experience of guilt in relation to childcare was common among mothers. They described how they were trying to manage the balance between participating in working life and at the same time fulfilling the expectations of being a good mother (Elvin-Novak, 2001). On the contrary, many fathers expressed satisfaction with their contribution as parents in general.

2.10 Theoretical Perspectives of Support Services

2.10.1 The medical versus socio-ecological model of disability

Pledger (2003) suggested that there were two basic ways to understand disability: the medical model where disability is understood in terms of functional loss and impairment, and the social-ecological model where disability is understood as a mismatch between personal competence and environmental demands. The implication of a medical understanding for those involved in providing human services to people with disabilities is to try to fix the person. Increased personal independence (i.e., being less reliant on others for assistance) is valued. A human services mission that is consistent with a medical understanding of ID involves pursuing either a complete cure (i.e., complete independence) or a partial cure; i.e., less dependence (Thompson and Viriyangkura, 2013).

In contrast, human services to people with disabilities that are based on a social ecological understanding of disability do not focus efforts on curing a person. Rather, what needs to be "cured" is the context in which the person functions (i.e., fixing the mismatch between the person and the environment). The focus of human services is on arranging personalized supports that effectively bridge the person/environment gap. Effective supports (and effective human services) result in the person with ID more fully participating in the same types of settings and activities that are accessed and valued by the general population (Viriyangkura, 2013). The above statement does not mean that teaching new skills to a person is inconsistent with social-ecological understanding of disability. Teaching can be consistent with social-ecological understanding of disability if the skills being taught are useful in settings and activities in which the individual desires to participate. The goal of teaching new skills, however, is not to change people so that they have less of a defect, but rather to empower people to function more successfully and participate more fully in their environments and activities (Thompson and Viriyangkura, 2013).

2.10.2 Stress and Coping Theory

The dominant theoretical perspective in social support research draws from stress and coping theory (Lakey and S. Cohen, 2000). According to this theory (Lazarus and Folkman, 1984; Folkman and Moskowitz, 2004), stress occurs when people interpret situations negatively (i.e., negative appraisals) and stress leads to health problems, in part, insofar as people do not employ adequate coping responses (e.g., problem solving, emotion regulation). Social support promotes health by protecting people from the adverse effects of stress (i.e., stress buffering; Cohen and Wills, 1985). It does so by promoting more adaptive appraisals, more effective coping or both. The appraisal theory examines the process by which emotions are elicited as a result of an individual's subjective interpretation or evaluation of important events or situations; hence, it is the evaluation of events that determine one's safety in relation to his or her place in the environment (Lazarus, 1999). Therefore, an event, irrespective of its importance, may or may not be perceived as stressful or harmful by an individual (Regehr and Bober, 2005). The appraisal perspective predicts that beliefs in the available support (perceived support) influence appraisals of stressful situations, which buffer the effects of stress on health outcome.

Stress has traditionally been viewed as a response, a stimulus, and, most recently, as a transaction stress. Specifically mental stress is defined as a transaction when the cognitive focus is on the relationship between the person and the environment, such as thinking about events in one's life and deciding if one has the personal resources to handle those events (Lazarus, 1999). The feeling of being physically, mentally, socially or economically weighed down or burdened as a result of having or caring for an ID child is defined as stress for the purpose of this study.

Previous research has established connections between social support and positive relational and health outcomes, leading scholars to pinpoint adequate support as a key resource for people facing chronic stressors like those experienced when providing care for a child with disabilities (Cohen and Willis, 1985; Lovell, et al., 2012).

A study in the United States titled "*Supporting the Supporter: Social Support, Stress, and Wellbeing among Caregivers of Children with Severe Disabilities*" explores how support and its quality influence the physiological stress responses of both the support receiver (a caregiving parent of a child with disabilities) and the support provider (a network member of the parent) (Meara, 2014). The findings indicate that both perceived support and enacted support significantly affect the health of the support recipient as measured through self-reports and physiological data examining participant experiences of stress. Specifically, global perceived support was found to affect participants' reports of depression and anxiety by influencing their self-reported perceptions of stress. Similarly, results from the supportive interaction indicated that receiving support can result in positive changes to physiological stress (Meara, 2014).

The study further hypothesized to explore how parents' perceptions of support influenced their levels of perceived stress, subjective mental health, physical health complaints, and relationship outcomes with their conversation partners**.** The findings demonstrated that the relationship between perceived support and self-reported mental health was mediated by perceived stress (Meara, 2014). These findings support the stress buffering hypothesis (Cohen and Willis, 1985), which states that social support positively influences wellbeing by protecting distressed individuals from experiencing heightened levels of stress. This indicates that social support serves an important protective function for parents of children with disabilities by guarding them against some of the negative effects of stress outcomes.

However the findings revealed that perceived support was not associated with physical health complaints, a finding that runs contrary to the stress buffering hypothesis (Meara, 2014). Though this study's findings point to interesting conclusions, it is not without limitations. It could also be possible that participants underreported or underestimated their own health ailments, as the instrument used to measure physical symptoms relied upon self-report data. The parents who participated were married (82.5%) and white (97.5%), as compere to Africa where many parents are divorce as result of the birth of disable child. Therefore findings are not representative of the greater population of parents who care for children with disabilities. It is possible that parents experiencing lower access to support, lower socioeconomic standing or a combination of the two could respond to and benefit from supportive attempts differently than people without these challenges. This call for further research to explore the connections between perceptions of support, perceived stress, and health in general of parents with children with disability. This, in turn, might lead to greater insight and illumination regarding the relationship influence of perceived support, actual and perceived stress, and physical health outcomes.

2.10.3 Conceptual Framework on Support Services to Parents with Intellectually Disabled Children and its contributions

The conceptual framework which is guided by the appraisal perspective of stress and coping theory for the study is illustrated in figure 1 below

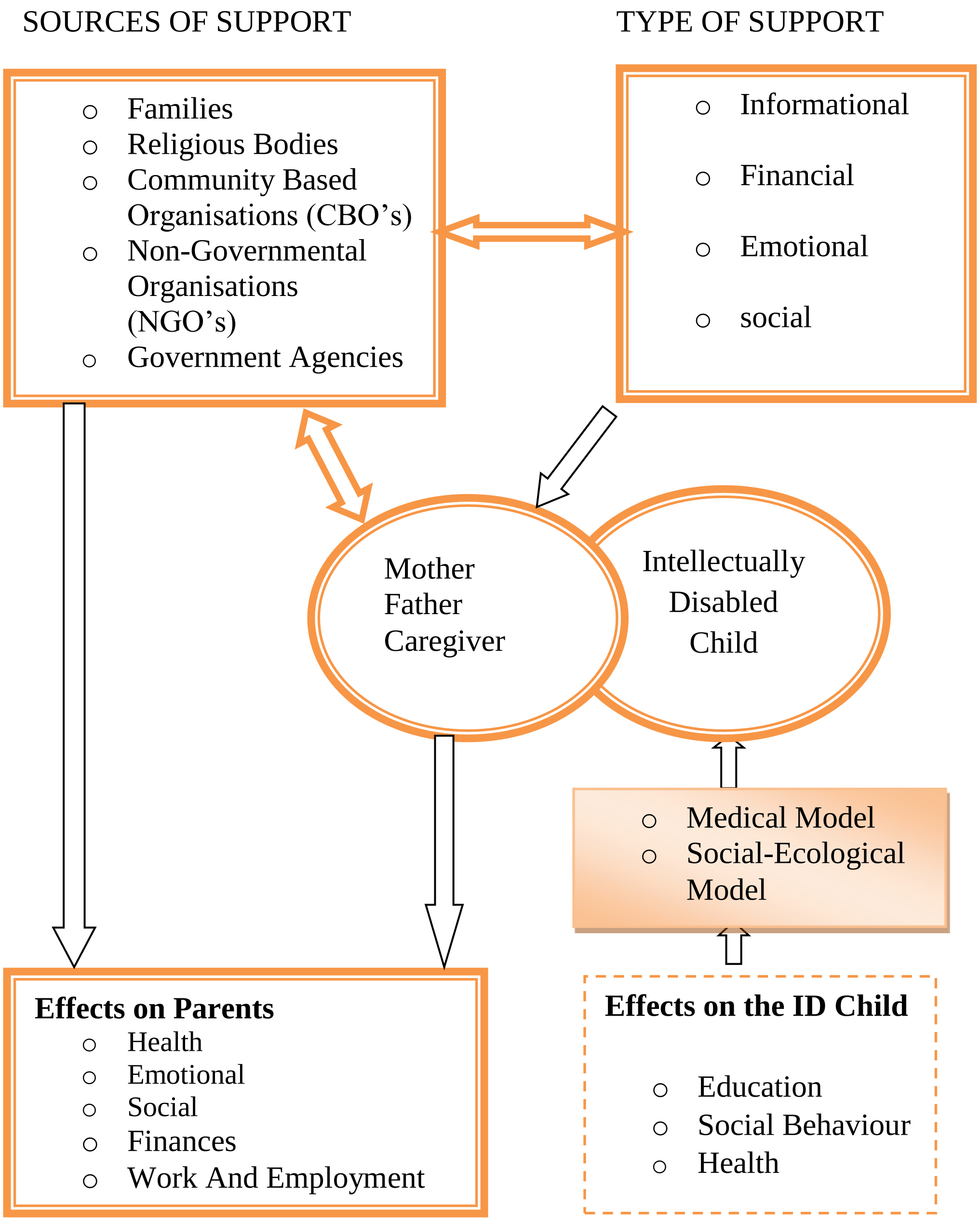


Figure 1: Conceptual Framework on Support Services to Parents with ID Children and its contributions

Sources: Author's construct (2017)

The above conceptual framework was drawn from appraisal perspectives of the stress and coping theory. Appraisal refers to individuals' evaluation of the significance of what is happening for their well-being, and coping. According to Folkman and Lazarus (1980), coping refers to “the cognitive and behavioral efforts made by parents to master, tolerate, or reduce external and internal demands and conflicts among them” as result of caring for the ID child (Folkman and Lazarus, 1980: 223). These two concepts are central to psychological stress theory. From the figure 1 above, the supports such as informational, financial, emotional and social support are thought to reduce the effect of stressful parental challenges and enhance coping performance (i.e. act as a stress buffer). Also, parents’ belief that these support are available or perceived to be available support from the family, religious bodies, the community, NGO’s CBO’s, and government agencies may lead to appraisal of potentially threatening situation of caring for the ID child less stressful.

Consequently, parents and support providers appraised the effects of support services subjectively on parent’s: health (mental and physical health), emotion (provoking feelings that mothers experienced such as disappointment and heartbreak) work (difficulties mothers experienced with their employment or work) and financial stress (monetary difficulties face by mothers), social relations (difficulties mothers experienced regarding their interaction with family, friends, neighbours and society in general) , child Education (development of social skills), health (physical health), and Social behaviour (degree of dependence and display of challenging behaviour in the child). In the context of research, larger studies investigating child characteristics typically use one parent’s ratings of the child – most commonly the mother’s (Seifer, Sameroff, Dickstein, Schiller, and Hayden, 2004). When investigating child’s characteristics, researchers aim to collect descriptions of children that are as close to “objective reality” as possible. What is implied by objective reality is not easily defined, but it is of great importance to clarify what informants base their ratings on. Different types of informants such as teachers, parents and children tend to differ in their descriptions of child characteristics (Achenbach et al., 1987). However, agreements between informants who are in a similar relationship to the child such as teacher or mother-father tend to be higher suggesting situational specificity (Achenbach et al., 1987).

Stress can be appraised as ‘‘healthy,’’ especially when the stressor is perceived as a challenge, which can thereby influence individuals to be more flexible and adaptive in their response to stressors (Esch, 2002). Parents and support providers appraised the effect of support service on ID children based on medical or sociological perspective of disability. Results from studies of parental representations indicate a high level of subjectivity and affective content in parents’ descriptions of their children. Despite this, parents are commonly used as informants of child characteristics and clinicians rely heavily on parents’ reports about child symptoms when diagnosing emotional and behavioural problems (Achenbach et al., 1987: Boström, 2012).

2. 11 Summary of Chapter

From the literature, it is evident that caregiving to Intellectually Disabled children affects all aspects of parents’ life including mental, physical, emotional, social and economic. The sources of support could be formal or informal. Informal care is provided by families and friends, and formal services provided by government, non-profit organizations, teachers, social organisations and for-profit sector Empowerment through disability rights organizations. The type of supports available to parents and caregivers were in the areas of: informational, emotional, and practical assistance, network, and esteem, informational, tangible, and emotional support.

The empirical evidence on the impact of support services on parents shows that parents with greater perceived support experienced lower levels of psychological distress and fewer physical health complaints than caregivers experiencing lower levels of perceived support. An additional finding also shows that, if parents have improved quality of life, mental health and wellbeing, it was also possible that these benefits could be transferred to their children.

However, the majority of this documented evidence came from studies that were conducted in the western world with only a few emanating from Africa. Also, the disproportionate majority of the studies reviewed employed quantitative approach in answering their research questions. This study was therefore imperative in the quest to ascertain the veracity of these earlier studies and their applicability in the Ghanaian and African context. The present study also employs a qualitative approach to explore the effects of support service on parents with intellectually challenged children and their children in the Nkoranza South Municipality of Ghana. It documents the main sources of the support services, what kinds or types of support where available and their effects on both parents and the ID children themselves.

What signifies the situation of parents of children with ID in the developed world is that, they seem to experience many of the same difficulties as parents in other parts of the world. Despite the relatively generous social and economic support available for those families, some parents experience difficulties getting access to such benefits, which may add further strain. Many Swedish couples appear to have a traditional division of responsibilities, while there is a tendency among others to strive towards equality – a diversity that could also be expected to be found among parents of children with ID.

CHAPTER THREE

RESEARCH METHODOLOGY

3.0 Introduction

This chapter presents the methodology of the study. It constitutes the study area, research design used to anchor the study, the target population, sampling technique, sample size, data collection procedure, data analysis and ethical consideration.

3.1 Study Area

The Nkoranza South Municipal served as the study area. A report by Ghana Statistical Service (2013) indicates that, Nkoranza South Municipality was carved out of the Nkoranza District in February, 2008 by Legislative Instrument (LI) 1899, and in May, 2012 it was upgraded to a municipality status. The main economic activity in the municipality is agriculture. According to Ghana Statistical Service report (2013), there are 1,745 persons with one form of disability or other constituting 1.7 % of the total population in the Municipality (GSS 2010).

The commonest type of disabilities recorded in the 2010 census in the Municipality are physical impairment 33.4% followed by sight related impairments 26.6%, intellectual disability constitutes 20.5%, speech 18.7% emotional 18.2%, hearing 17.9% and others 9.6%. The disability rate is high among the age group 5 – 9 years 9.9% followed by 15 - 19 years 8.9%. Age 95 years and older recorded the lowest rate of disability 0.8%. Also more than half of Person with Disabilities (PWDs) 53.3% is employed and close to 47.1% of PWDs have never attended school (GSS 2010). The municipal capital is one of the towns in Brong Ahafo Region blessed with Hand in Hand Peace of Christ Community (PCC), a home for abandoned and mentally handicap children and a shelter work school for the mentally disabled and Shalom Special School for the Intellectually Handicap. Nkoranza cannot be left out in the history of social protection since the first Mutual Health Insurance Scheme (MHIS) in Ghana was introduced in Nkoranza. It was initiated by the Catholic Diocese of Sunyani in 1989. As such, the researcher felt that focusing the research in the municipality was convenient and would allow the researcher greater access to parents of children with ID (as they would potentially be seeking services in Nkoranza) as well as professionals, officials and agencies involved in the service provision for Persons With Disability.

Map of the Study Area

Figure 2: Map of Nkoranza South Municipal

Source: Ghana Statistical Service, (GIS 2013)

3.2 Research approach

Research approaches are plans and the procedures for research that span the steps from broad assumptions to detailed methods of data collection, analysis, and interpretation. The three research approaches advanced are qualitative, quantitative, and mixed methods (Creswell 2014). The qualitative approach is used when aiming to find an in depth understanding into a phenomenon, thus when the research topic is exploratory in nature. It usually aims to answer questions about the "what", "how" or "why" of a phenomenon rather than "how many" or "how much", which are answered by quantitative methods (Bricki, 2007), and it involves few cases with many variables (Yin, 2009). On the other hand, quantitative research is an approach for testing objective theories by examining the relationship among variables and use of numerical terms to explain data. While mixed method research is an approach to enquiry involving collecting both quantitative and qualitative data. This normally involves integrating the two types of approaches and using distinct designs that may involve philosophical assumptions and theoretical frameworks (Neuman, 2007). However, considering all these three approaches, the researcher employed the qualitative approach for the study based on the purpose of the study to answer the "what" and "how" questions than testing hypothesis to explain variables.

Leaning on Cresswell (2014), a researcher conducts qualitative research because the researcher need a complex detailed understanding of meaning individuals or groups ascribe to a social or human problem. Regarding the intent of this study and deciding to use the qualitative approach provided the researcher the chance to explore deep into the actual situation on the ground from the parents' own experiences as well as the support service providers. Qualitative method was also the best approach to use as the study sought to have an in-depth analysis on how support services available influence the wellbeing of both parents and ID children. Moreover, qualitative research can be used when exploring a less researched area and little research has been done into support provision for parents and their ID children in Ghana.

3.3 Research Design

In conducting a social research, research design helps the researcher decide on the type of methods and procedures to be used to study the problem under investigation. Thus, research design provides the specific direction for the study (Creswell, 2013). In qualitative approach, designs include: narrative, phenomenology, grounded theory, ethnographies and case study designs (Creswell, 2009).

Yin (1991) defined case study as an empirical inquiry of a contemporary phenomenon within its real context using multiple source of evidence. The term "case study" can refer to either *single*- or *multiple-case studies*, they represent two types of *case study designs* (Yin 2004). In this qualitative study, the method of single case study strategy of inquiry was employed for the study. This allowed the researcher to explore in depth information using a variety of data collection procedures from respondents over a sustained period of time. Yin (2004) postulated that, a case study design gives in-depth information from the respondents that give an empirical inquiry to investigate a contemporary phenomenon within its real-life context. Though having multiple three or more cases with geographic, ethnic, size, or other related variation among the cases might help the researcher to strengthen the findings from the entire study—however, Focusing on a single case forced the researcher to devote careful attention to the case of parents with ID children (Yin 2004).

The case study method is best applied when research addresses descriptive question (what happened?) or an explanatory question (*how* or *why* did something happen?), subsequently, the study sought to find out regarding what support services are available to parents of intellectually disabled children and how it is contributing to the wellbeing of both parents and children (yin 2004). The case study approach employs several data collection methods in order to avoid errors. Mostly observations and interviews are used in case studies (Creswell 2014). The respondents (parents and support service providers) in this type of research are treated as experts instead of mere source of data (Sarantakos, 1996). A case study is often associated with a location, for example, an organization or a community. In this case, Nkoranza municipality and agencies within that provide support services to parents with ID children (Bryman 2004). Thus, this study employed a single case study as an approach to gain an in-depth understanding of support services available to parents of intellectually disabled children and how it is contributing to the wellbeing of both parents and children with the aim of producing a first-hand understanding of their experiences.

3.4 Target Population

In this study, the target population comprised parents of Intellectually Disabled children and key informants from Shalom Special School for Intellectually Handicap, Peace of Christ (PCC) Hand in Hand Community, Department Of Social Welfare and Community Development and Ghana Federation of the Disabled (GFD) in the Nkoranza South Municipality of the Brong Ahafo Region. According to Creswell (2013), the study population is the larger population of the study area while the targeted population is the sub group of individuals to which researchers are interested in generalising the conclusions.

3.5 Sampling Technique

In research, sampling allows the researcher to select a few proportions of individuals or groups from a bigger group or population. According to Babbie (2010) the rationale behind sampling is that in research it is difficult to cover the entire population due to practical reasons such as time factor and inadequate resources. In this study, the researcher employed purposive and snowballing sampling technique as part of non-probability sampling technique to select respondents such as parents and caregivers of intellectually disabled children and other key informants. According to Neuman (2012), purposive sampling is a valuable kind of sampling for special situations such as unique cases where members have in-depth knowledge about the problem under study.

In conducting the study, the purposive sampling begun with the enlistment of respondents through initial contact with institutions in the study area that provides services to children with intellectual disability to assist in locating parents. These institutions were PCC Hand in Hand Community and Shalom Special School for Intellectually Disabled in Nkoranza. The institutions provided the records of pupils who come from Nkoranza South Municipality, their addresses and contact numbers of their parents. Thus, parents were selected by virtue of the fact that they resided in the Municipality and had at least one ID child who is below 18 years.

Subsequently, purposive and snowball sampling techniques was used to select key informants from Non-governmental, civil society and government organization for data gathering based on the following criteria:

1. A staff with over five years' experience in the organization that provides support services to persons with disability
2. A staff with an in-depth knowledge about the support services the organization provides and directly involved in the support provision for over 5 years.

Respondents who fulfilled these criteria were contacted through telephone calls and home visits. Upon receiving their consent, the researcher asked each of them about a convenient time, date, and place for the interview.

A snowballing method was used in an attempt to reach other potential respondents whose children were not in the stated facilities but equally were raising ID children in the area. Snowballing is a method of sampling that asks other participants or community members to identify more individuals that could also be information-rich for the purposes of the study (Creswell, 2007). Researchers suggest that using this type of approach to sampling enhances the identification of a greater number of individuals affected by the phenomenon and yields rich information about the social networks, grassroots organization, and social dynamics of the individuals involved in sampling (Noy, 2007).

3.6 Sample Size.

A total of twenty three (23) respondents met the researcher's criterion of selecting respondents for the study. The breakdown are as follows; ten (10) ID parents, six (6) caregivers and seven (7) key informants from Non-governmental, civil society and government organization that provide support to parents and their ID children . This is shown in Table 1

Table 1: Characteristic of Sample Population

Characteristics	**Frequency**	**Percentage %**
Sex		
Male	7	30
Female	16	70
Subtotal	**23**	**100**
Age		
30 -39	5	22
40 49	7	30
50 +	11	48
Subtotal	**23**	**100**
Education		
Tertiary	6	26
SSS/Middle School	5	22
JHS/ Primary	9	39
None	3	13
Subtotal	**23**	**100**
Marital status		
Married	6	26
Single	4	17
Widow	8	35
Divorce	5	22
Subtotal	**23**	**100**
Employment status		
Waged employment	8	35
Farming/ Trading	13	56
Unemployed	2	9
Subtotal	**23**	**100**
Relationship to the child		
Biological	10	43

Caregiver	6	26
Support providers		
Department of Social Development	2	9
Peace of Christ, Hand in Hand Peace Community	2	9
Shalom Special School for the Intellectually Handicap	2	9
Ghana Federation of the Disabled (GFD	1	4
Subtotal	**23**	**100**
Grand Total	**23**	**100**

Source: Author's field data (2017).

3.7 Data Collection Instrument and Procedure

In line with the case study design, a semi-structured interview and observation were used to collect data. Semi-structured interview is quite flexible which allows the researcher to decide the sequence and wording of questions in the course of the interview but guided by a checklist (Sarantakos, 2013). In order to collect data, two different semi- structure interview guides with open-ended questions for parents and support providers respectively were developed to gain insights into the support services available to parents of intellectually disabled children and how it is contributing to the wellbeing of both parents and children. However, observations and semi-structured interview guides were used to explore the parents' experiences of available support services. This encouraged the respondents to produce detailed answers, rather than 'yes-no-maybe' types of responses. These tools respond to the critiques of quantitative methodologies that are characterised by limited interaction between the researcher and the participants and its focus on 'objectivity' (Cieslik and Simpson, 2013).

An in-depth one- on- one interview was conducted in two phases. The first phase was the interview of the parents and the second phase was the interview of the support providers. The interview guide was written in English, and the interviews were conducted in English, and in Twi which is the indigenous language of the people in Brong Ahafo Region. Because of the sensitive nature of the questions and in other not to use offensive Twi language during the interview, a research assistant who was an indigene and fluent in the local language assisted the researcher in the conduct of the interview. Each interview took approximately thirty minutes and a mobile phone recorder was used to record responses to the questions with permission from the respondents. All interviews were held in the respondents' home and workplaces.

Since most qualitative interviews are between strangers, the interviewing process requires establishing a rapport that allows for an openness of exchange (Rubin and Rubin, 2005), and clarity of the guiding questions particularly at the initial stage. Parent respondents were asked to reflect on their experiences when they realized they had given birth to an intellectually disabled child and support services they received. Responses were probed or redirected when necessary to maintain focus.

The researcher also kept detailed field notes of the environment, nonverbal cues, interruptions, personal reflections about observations made during the interviews among other things using Observational protocol. Observational protocol is a form used by a qualitative researcher for recording and writing down information while observing (Creswell, 2013). Data collection started in February 2017 and ended in March 2017.

3.8 Data Analysis Procedure

Content Analysis was relevant as a methodological tool to analyze the text and audio responses. Thematic Content Analysis (TCA) is a descriptive presentation of qualitative data, this method involves looking across all the data to identify the main themes that summarize all the views that will be collected (Anderson, 2007). With the help of the research assistant, all audio recordings were transcribed verbatim and separately in order to differentiate what each participant said into text format in English. The final transcripts were read several times to identity concepts and broad ideas that are related to the objectives of the study. These concepts and broad ideas were given alphabetical codes. Concepts and ideas that are related in each interview were given the same alphabetical codes. All concepts and statements that were similar or have similar meanings from all the individual interviews were grouped under one theme.

Validity is one of the strengths of qualitative research and is based on determining whether the findings are accurate from the standpoint of the researcher, the participant, or the readers of an account (Creswell 2014). In analyzing data, the researcher checked for validity by comparing information generated among parents and support providers through interview and observation and information gleaned from the literature. The researcher paid particular attention to how respondents answered questions and observed that there were common patterns in their experiences. By making this comparison and observation, information obtained could be considered as representative of the phenomenon at hand and its validity can be deemed appropriate. According to Creswell, (2013) if themes are established based on converging several sources of data or perspectives from participants, and then this process can be claimed as adding to the validity of the study.

Qualitative reliability indicates that the researcher's approach is consistent across different researchers and different projects (Gibbs, 2007 cited in Creswell 2014). The researcher checked and read the final transcripts several times to make sure that they do not contain obvious mistakes made during transcription. Gibbs (2007) suggests that this check is one of several qualitative reliability procedures. The researcher has also provided detailed description of the research design, procedures used in collecting and analyzing the data, and background information of respondents. Yin (2009) suggested that qualitative researchers need to document the procedures of their case studies and to document as many of the steps of the procedures as possible. The researcher presented and interpreted themes based on the frequency and consistency of shared experiences or perspectives reported by respondents.

A major concern of case study is generalizing findings, because it is limited to a particular area. It is one of the most common misconceptions to believe that case studies are to represent a formal "sample" from some larger universe, and that generalizing from cases depends on statistical inference (*statistical generalization*); instead, generalizing from case studies reflects substantive topics or issues of interest, and the making of logical inferences (*analytic generalization*)(Yin 2004). Thus, investigating support services available to parents of ID children are substantive topics or issues of interest to families, caregivers, national government, non-governmental organization, United Nations Children Fund (UNICEF, 2007) and therefore the finding can be generalized.

3.9 Ethical Consideration

In social research there are three main ethical issues that have to be considered in conducting research, i.e. maintain professional standards, voluntary consent and anonymity (Sarantakos, 2013). In conducting the study, a formal permission was sought from shalom Special School, PCC Hand in Hand Community, Department of Social Welfare and Community Development and Ghana Federation of the Disabled (GFD) in Nkoranza South Municipality with an introductory letter from the Faculty of Integrated Studies, of the University for Development Studies stating the purpose of the study. Prospective respondents were taken through the consent process and were made to sign or thumbprint on the informed consent form prior to the commencement of the interview. To ensure confidentiality, the interviews did not involve both partners at the same time, because interviewing two people who are involved in an intimate relationship has inherent ethical and procedural challenges (Forbat and Henderson, 2003). To ensure anonymity, all names of respondents and their children were replaced with pseudonyms to protect their identities. The researcher conducted the study in consonance with the University's ethical standards.

3.10 Limitations of the study

Some potential parent respondents whose children showed signs of ID were not interviewed because they did not have any documented medical report for the researcher to ascertain that the condition of their children is ID.

One major limitation is the inadequate relevant literature from the Ghanaian context, as few empirical studies have been undertaken in Ghana. Since information in developing countries is very limited, the literature tends to focus mostly on western literature on disabilities with few ones from Ghana. Another constraint that had to be faced was finance because the researcher had to rely on his limited resources to meet the cost of the entire studies.

3.11 Chapter Summary

The Nkoranza South Municipal served as the research location. The researcher focus on the municipality was convenient and allowed greater access to parents of children with ID as well as professionals, officials and agencies involved in the services provision for PWD. The researcher employed qualitative approach and the method of single case study strategy of inquiry to explore in-depth information to answer "what", and "how" research objective questions of the study. Subsequently, purposive and snowball sampling techniques was used to select sample size of twenty three (23) respondents made up of parents and key informants. The study employed variety of data collection procedures that is semi-structured interview and observation for Data Collection. Data was analyzed using Thematic Content Analysis and presented and interpreted in themes based on the frequency and consistency of shared experiences or perspectives reported by respondents. Respondents were taken through informed consent process, ensuring confidentiality and anonymity of respondent's information were some of the Ethical Consideration the researcher considered.

CHAPTER FOUR

DATA PRESENTATION, ANALYSIS AND DISCUSSION

4.0 Introduction

This chapter deals with the presentation, analysis and discussion of results obtained from the study. The chapter begins with a presentation of the demographic characteristics of the respondents. The results are then presented according the objectives of the study. Sub-themes were identified from respondent's subjective descriptions of their experiences of support services they received. The first objective was geared towards identifying and examining the sources of the support services. The second objective was to identify and describe the type and nature of support services available to parents, and the third was to describe the effects associated with the support services on the lives of parents and their ID children in the Nkoranza South Municipality.

4.1 Demographic Characteristics of Respondents

The demographic characteristics of the respondent include sex, age, educational status, marital status, relationship to the child and names of support service. The respondents of the study were largely female representing 70% of the total respondents while the males constituted 30%. The sample was so because, usually in the African and Ghanaian setting, the onus of caregiving to persons with disability is tended to be the skewed disproportionately towards females who become the primary caregivers.

The ages of the respondents ranged from 30 to 60 years, with nearly half of all respondents 48% been 50 years and above, the remaining were distributed as follows;

30% and 22% were within the ages of 40-49 and 30-39 respectively. There were no respondents below the age of 30 years.

On education the 23 respondents had diverse educational backgrounds. The highest educational attainment of the respondents was tertiary which was attained by of 26% of respondents, while, 39% had completed either Junior High school or Primary school, 22% were SSS or Middle School leavers. The remaining 13% of the respondents had no formal education at all.

On marital status, the results indicate that, 35% of the respondents were widows, while 26% were married, 22% were divorced, while the remaining 17% were not married. This means that, at present, it could be asserted that 74% of respondents were currently single or unattached. In terms of occupation, 13 of the respondents, representing 56% were farmers who occasionally engaged in other businesses like petty trading to support their farming. Apart from this, 35% of the respondents had formal occupations such as teaching and caregiving. Also, 9% reported that they were too old to engage in active work.

With respect to the relationship of the respondents to the children, 43% were the biological parents of the children; while 26% were caregivers, and 31% were support providers to parents and their ID children.

4.2 Sources of the Support Services to Parents with ID Children.

The first objective of the study was to identify and describe the various sources of support available to parents of ID children in the municipality. To do this, the data was collected from the various organizations. The researcher identified the history, mission, core activities, and the specific support services the various organisations provided to parents and their ID children.

Parents identified Non-Governmental Organisations (NGOs), and Government agencies as key providers of economic and social support services. The main pro-poor support service providers were the Department of Social Welfare and Community Development, Ghana Federation of the Disabled, Shalom Special School for the Intellectually Handicap and Peace of Christ Hand in Hand Community. Following the identification of these agencies and institutions, the researcher sought to find out from these agencies, what their policies on support services were and how they went about extending these support services to the targeted beneficiaries.

4.2.1 Department of Social Welfare and Community Development (DSWCD) and Allied Agencies

The Department of Social Welfare (DSW) was established in 1946 and derived its mandate from statutory orders that made it responsible for social services encompassing health, housing, education and agriculture. Over the years, its mandate has been redefined under various ministries. With the promulgation of LI 1961, the Department of Community Development and Department of Social Welfare at the local level have now been merged to become a department of the Metropolitan, Municipal and District Assemblies, (MMDAs). Presently the Head Office of the DSW is an integral part of the Ministry of Gender, Children and Social Protection.

Social Support Services provided by the Department and other Agencies

The Department of Social Welfare and Community Development classified their activities under four core programmes namely:

1. Child Rights Promotion and Protection,
2. Community care,
3. Justice Administration,
4. Budget and Planning.

With reference to Social Welfare and Community Development Training Manual, the key informant of the DSWCD in the Nkoranza Municipal Assembly revealed that, under the child rights promotion and protection are activities such as maintenance of children, child custody, paternity, adoption, running of children homes, and supervision of day care centers. Community care programme runs such activities as Hospital Welfare Services, Psychiatric Social Work Services, Services for the Destitute, Registration of NGOs, Community Based Rehabilitation, provision of vocational training for the poor and disabled, income generation for rural women, and poverty alleviation through LEAP. The justice administration division deals with probation and prisons aftercare services as well as domestic violence (Local Government Service 2014).

In answering questions on the role of the agency in the provision of support service to parents with ID children, the key informant of the DSWCD further revealed that, the Department of Social Welfare as per the assembly regulation has no specific programme for parents of intellectually disabled children. However, their supports are captured under the District Assembly Common Fund for Persons with Disabilities, and government social protection interventions for the venerable people such as LEAP, free registration and renewal of their health insurance and free school uniform.

The Key informant of DSWCD revealed that,

"The Intellectually disabled children are entitled to the LEAP, common fund for persons with disabilities, renewal of their health insurance and free school uniform. In fact per the criteria for the selection of beneficiaries for LEAP, the mentally challenged automatically qualify"

LEAP

The LEAP programme is managed by the Ministry of Gender, Children and Social Protection (MOGCSP) and implemented by the Department of Social Welfare. Eligibility of beneficiaries is based on two criteria, (1) the household being considered poor, and (2) the household having a member in one or more of three demographic categories: (a) orphans or vulnerable children, (b) elderly people, or (c) people with disabilities and unable to work. The cash transfer is awarded to the household rather than the individual but the transfer amount is dependent on the number of 'eligible beneficiaries' per household (LEAP Operational Manual, 2008). The selection of households is done at the community level by Community LEAP Implementation Committees (CLICs) and verified by a proxy means test. The key informant of DSWCD expressed that:

"Parents with ID children qualified for the LEAP intervention per the criteria of selection; however, parents who are residents of communities classified as poor according to Ghana Statistical Services were selected to benefit from the LEAP cash transfer in the municipality"

This implies that many of the poor parents with ID are denied of the opportunity to benefit from the programme due to the economic status of their community. It is not surprising that few respondents confirmed receiving support from LEAP cash transfer.

NHIS

The National Health Insurance Scheme (NHIS) is one of the pro-poor policies implemented by the government to ensure equal access to primary health care in the country, especially to the most vulnerable. This came to replace the infamous cash and carry system, which demanded that people paid at the point of medical services even before they were treated. The researcher in this direction investigated the level of access to NHIS by children with ID. The key informant of DSWCD revealed that,

"In addition to the cash transfer, parents who are beneficiary of the LEAP intervention also receive free enrolment in the National Health Insurance Scheme and are exempted from paying premiums and registration fees. The department works in collaboration with the special school and National Health Insurance Authority to register and renew the registration of pupil at the special school NHIS cards"

MMDAs

The District Assembly Common Fund (DACF) Act 1993 (ACT 455) specified portion of the common fund of the Metropolitan, Municipal and District Assemblies, (MMDAs), to the disabled community was seen by many as a very progressive development. The DACF ACT 455 stipulates that 2% of all common fund monies allocated to MMDAs must be used solely to serve the needs of People with Disabilities, (PWD), in the community. The researcher investigated how the department disburses the disability fund to beneficiaries. The study discovered that, the municipality is one of the best in Ghana in terms disbursement of the funds. The Disability Fund Management Committee comprising a representative of the local Ghana Federation of the Disabled (GFD), district representative of the National Council on Persons with Disability (NCPD), the head of Department of Social Welfare vets all applications from the various associations under the GFD. The key informant of DSWCD intimated that:

"Nkoranza Municipal has been able to streamline the disbursement of the Disability Fund and it is rated as one of the best in Ghana. I think we fall around grade A, the reason being that we have vibrant disability associations under the Ghana Federation of the Disabled. Normally what happen is that, we do not receive applications as it is done at other districts in the office of the Department of Social Welfare. All applications are directed to the associations under Ghana Federation of the Disabled, which is a confederation of so many associations: We have Ghana Blind Union, Ghana Society for Death and Dump, and Ghana Association of Physically Challeng"

It could be gleaned from the statement above that, the department works in collaboration with Ghana Federation of the Disabled (GFD) to disburse the fund.

The researcher in this direction investigated the role of GFD in the provision of support service to parents with ID children. The key informant of GFD indicated that GFD is a national umbrella disability organization, established in 1987 as a pressure group. GFD is recognized and accepted nationally and internationally as the face and voice of disability in Ghana. Ghana society of the Physically Disabled (GSPD) is a vibrant member of GFD that performs Core activities of GFD at the municipal level. In answering a question on the role of GFD in the provision of support service to parents with ID children the key informant of GFD confirmed that:

"Ghana Federation of the Disabled is a confederation of many disable associations: In Nkoranza here the society of the Physically Challenge is well organized. However, there are some persons with other forms of disabilities. The association represents the disability community in advocating for the formulation of policies and equal opportunities at the Municipal Assembly. We also accept application from qualified applicant for the disability fund"

This finding affirms the assertion by parents that, GSPD as a support network facilitated the disbursement of disability fund when they register their children with them. It was uncovered that, there was no association for the intellectually challenged persons in the municipality.

The DSWCD work in collaboration with the National Health Insurance Authority, Ghana Education Services (GES) and PCC- Hand in Hand Community to provide the needed support services to the disability community in the municipality. The DSWCD support PCC- Hand in Hand Community with the disability fund to undertake advocacy and data collection projects that benefits children with disabilities within the municipality**.** The key informant of DSWCD revealed that:

"The department sponsor Peace of Christ Foundation per their advocacy programme for the children with disabilities. PCC have compiled data of mentally challenge and children with multiple disabilities for both Nkoranza North and South"

4.2.2 Shalom Special School for the Intellectually Handicapped

Another source of support indicated by parents was the Shalom Special School for the Intellectually Handicapped. Ghana considers a quality human resource base as very crucial in its development efforts to ensure socio-economic well-being of its citizens. It emerged frequently in conversations with parents that Shalom Special School for the Intellectually Challenged was a key provider of support services to them and their children. This was equally corroborated during key informant interviews with caregivers in the school. The respondents disclosed that, the School was established in September, 1997 to educate the intellectually disabled children in Ghana. The school was the brainchild of Dr. Ineke Bosman, a German medical doctor at St. Theresa's Hospital in Nkoranza and the founder of non-governmental organization Peace of Christ- Hand In Hand Community in Nkoranza. The school has now become a state-owned and has a pupil population of one hundred and fifty one (151).

Core activities of the Shalom School for the Intellectually Handicapped

The school seeks to provide some education and training to children with intellectual disabilities in the Brong Ahafo region and beyond. A key informant disclosed that the school's vision is helping ID children to acquire some pre-vocational skills that will help them to acquire vocations in weaving, bead making or animal rearing. Other core activities of the school also include teaching subjects like fine motor skills, gross motor skills, paper weaving using weaving frames, number work, writing skills and sporting activities.

In addition, a key informant further expressed that:

"*We attach pupils to the PCC 'Sheltered Workshop'. The Sheltered Workshop is situated in the community and is meant to provide work and vocational training for the mentally handicapped youngsters who live at the Hand in Hand Community and surrounding villages.*

The school receives feeding grants and school uniforms from the government of Ghana. We have boarding facility which houses children outside Nkoranza town, with 76 pupil in the boarding house, whiles 75 of them are day students"

Apart from the teaching staff, the school has three caregivers, and two cooks who are responsible for the welfare of the pupil in the school. The school has a fleet of vehicles which was provided by PCC, and the government of Ghana to ease movement of students to sporting and cultural programme in other schools. The school has a Parent Teacher Association (PTA) where parents together with teachers share experiences every term. The key informant expressed that admission of pupil into the school is strictly based on medical report from a recognized health practitioner.

"We should have a multidisciplinary committee which comprises of a lawyer, a social worker, a psychologist and a medical doctor as part of the school management board to examine the children before admission but because of inadequate personnel, admission of the pupil is based on a holistic medical report from a recognized medical practitioner"

Caregivers expressed that, they do their best to provide most of the children's physical and emotional needs of caregiving in the school. Even though the school conducts in-service training for caregivers, they rely heavily on their parental experience and faith in God to care for the children. Caregivers expressed that, *"We are responsible for brushing their teeth, shaving their private parts, cutting of their finger nails, and preparing them for school. At school, we serve them their food and stay with them after school, We draw them close to ourselves as our own children………there was a day one of the children fell in a pit that day we didn't eat the whole day until he was found alive"*

Socially, caregivers enjoy the company of the children and take them to religious programmes without stigmatization and discrimination from the public. A Caregiver conveyed that:

"*I send them to church every Saturday and people are happy to see them"*

A key informant of the school reaffirmed the challenges parents encounter when attempting to provide basic needs to their ID children.

"When school reopens it takes parents two to three weeks before mothers report their children to school due to financial constraints".

To ameliorate the plight of parents in such circumstances, the school provides recommendation letters for parents to solicit for support from their various district assemblies and other service providers. The letter states that:

"TO WHOM IT MAY CONCERN, Master/Miss…………is a pupil of the above mention school. Parents of these children face challenges in provision of their educational needs. The Ghana Education Services and the government of Ghana do recognize the challenges and endorse non-governmental organisations (NGO), churches and philanthropist to collaborate and provide education for these children with special needs. Mr./Miss/

Mrs.……………..is a parent of the above child and would be pleased to be assisted. Signed: assistant Headmaster"

The school also undertakes advocacy programmes to create public awareness of ID, and the existence of such a school. Key informant expressed that:

"The school run advocacy programmes in collaboration with National Commission for Civic Education (NCCE) at various churches on Sundays and radio stations in the Brong Ahafo region specifically radio BAR Sunyani and Classic FM Techiman to education the general public that there is hope for ID children"

4.2.3 Peace of Christ Hand in Hand Community

Another source of support for parents with ID children came from a religious NGO called Peace of Christ Hand in Hand Community popularly known as "*Dr. Bosman*". This community was cited by parents as a major support services provider in the municipality. The "Peace of Christ (PCC) Hand in Hand Community" is a residential community for abandoned and intellectually disabled children. The PCC Foundation is a Non-Governmental Organization, first registered in Ghana in 1992.

It was reported during the key informant's interview that, in 1992, Dr. Ineke Bosman a Dutch-Ghanaian doctor in Nkoranza Saint Theresa's Hospital having discovered the plight of children born with disabilities, was inspired to create a loving family, the Peace of Christ (PCC) Hand in Hand Community. This became a home for abandoned and mentally handicapped children as well as a place for shelter, work and school for the mentally disabled. In fact, this community has become for them an extended family and a home.

The researcher further investigated how children are admitted into the community. The key informant recounted how recently one child who was abandoned by her parents was admitted into the community.

"………one of the children "Mariam" was abandoned at the community gate. Nobody knows her mother or father and the one who brought her. Majority of the children were abandoned at the hospitals,……..Periodically, management visit children's home and, orphanages such as Osu orphanage in Accra to assess the children and those whose condition need special attention are brought here and sometimes the Department of Social Welfare brings abandoned children and after assessment they are admitted"

As a result, PCC has about hundred intellectual or multiple disabled children from all over Ghana comprising Down's syndrome, autism, cerebral palsy while others suffer from various rare hereditary congenital diseases, and non-specific intellectual handicaps, often combined with epilepsy and physical handicaps. Many of these are cause by birth-injuries. The community has a team of fifty (50) caregivers and other workers. The caregivers live like parents with their children.

Core Activities of the Community

It was revealed in the study that, the services and activities for children in the Community include; physiotherapy, shelter workshops, day care, summer school, hydrotherapy, and speech programme. The children in PCC have been categorized into various groups according to their condition and special needs.

A key informant of the Community articulated the core activities of the place in the following statement;

"….from 7:00am to 8 am is time for exercise, so here at the "Physciopalace" we have children who undergo physiotherapy programmes. The rest of the children attend day care. We have sign language and Special Attention Child Programme managed by volunteers from Germany. At 4pm, all the children will come to the swimming pool to swim for 45 munities afterwards kids and caregivers have dinner and watch television together"

The community has shelter workshops where children are trained in vocational skills to be independent and contribute to national development. Again it was reported that;

"The shelter workshop trains children in Kente weaving, bead making, sewing, designing of party flags and drawing. Not all the children who study at the workshop are accommodated at the PCC. Most of those whose houses are closer to the PCC return home after trainings daily. The rest stay in our dormitories and go home only during vacation time"

The organization supports parents and children with multiple disabilities. These include cases that have been identified at the various communities who could not be admitted into the Community. In this regard a key informant asserted that:

"The organization has established home based center for children that could not be admitted in the community. The organization has identified and documented persons with ID and multiple disabilities in the municipality and supports some of the identified disabled children who leave with their parents or guidance at various communities"

It was further revealed that, the organization diagnosed and supported the identified children based on their special condition and needs.

"The epileptic groups are supported with medication monthly. However, we refer them to hospitals when the organization is short of drugs. Others are supported with wheelchairs to enable them walk, and some are supported with surgical bills"

In addition, the organization organizes radio advocacy programme and public durbars that create the platform to educate the public and create the awareness of the intellectual disability and the care they need.

"We organized radio advocacy programme because we realized this has affected the care given to them. The organization also provides counselling to the parents"

Thus, "PCC/Hand in Hand Community" provides a residential Community for abandoned and intellectually disabled children. The community has caregivers who serve as mothers of the abandoned children. They sleep together, play together, bathe their children, eat with them and send them to school. The caregivers also have general assignments in the group, such as running day-care, cooking, computer classes, and supervising the swimming-hours. Caregivers loyally adhere to a precise daily routine to ensure the safety of the children. Emphasis is laid on warmth; fun and love. The organization also provides a very interesting working place for about 5 - 6 foreign volunteers at a time. The volunteers assist PCC in the Special Attention Child Programme and others.

The community has a Physiotherapy centre, the "Physciopalace" with modern equipment and well-trained instructors for children who have physical difficulties. Additionally, children exercise and undergo hydrotherapy programme in a swimming pool every day to ensure total fitness. The community provides day care school for children while intellectually disabled children attended the Shalom Special School for Intellectually Handicapped. The ID children are taught home skills, basic alphabets in English and numerals, ICT skills, and sigh language whiles special monitoring for children with behavioral challenge.

The shelter workshop aims at equipping children with vocational and social skill. The above indicates that among other things, the shelter workshop forms an integral part of the Community where children receive training in bead and necklace making; glass beads, hip strings, bracelets and other beaded products. There are weaving halls which produce the best of African Kente in a variety of colours. Trained caregivers supervise all the processes involved in training these children.

4.3 Nature of support services to parents with ID children

A second major objective of this study was to discover the types and nature of support services being offered to parents with ID children from the various sources. The support services included all various types and forms of support available to parents with intellectually challenged children.

The first issue examined was how parents initially received the news of their children’s disability and their experiences from then on. Parents were asked to reflect on their initial experiences when they realized they had given birth to intellectually disabled children, the challenges they encountered, and the available support services they received. Most of the parents indicated that, they learned of their children’s disability within the first two years of birth. Only a few parents indicated that, the condition was identified a few days after birth.

In an interview, a parent recounts that:

"When I gave birth, my child did not cry, nurses tried all they could but it did not cry. After I was discharged, the child neither laughed nor opened its mouth to take in breast milk or even defecate for nine days" (Mother of a 17-year-old ID girl).

"He was a normal child from birth until he experienced convulsion. After the convulsion we realized that the child has speech problem and when he started walking we realized many defects" (Caregiver of a 15-year-old ID boy).

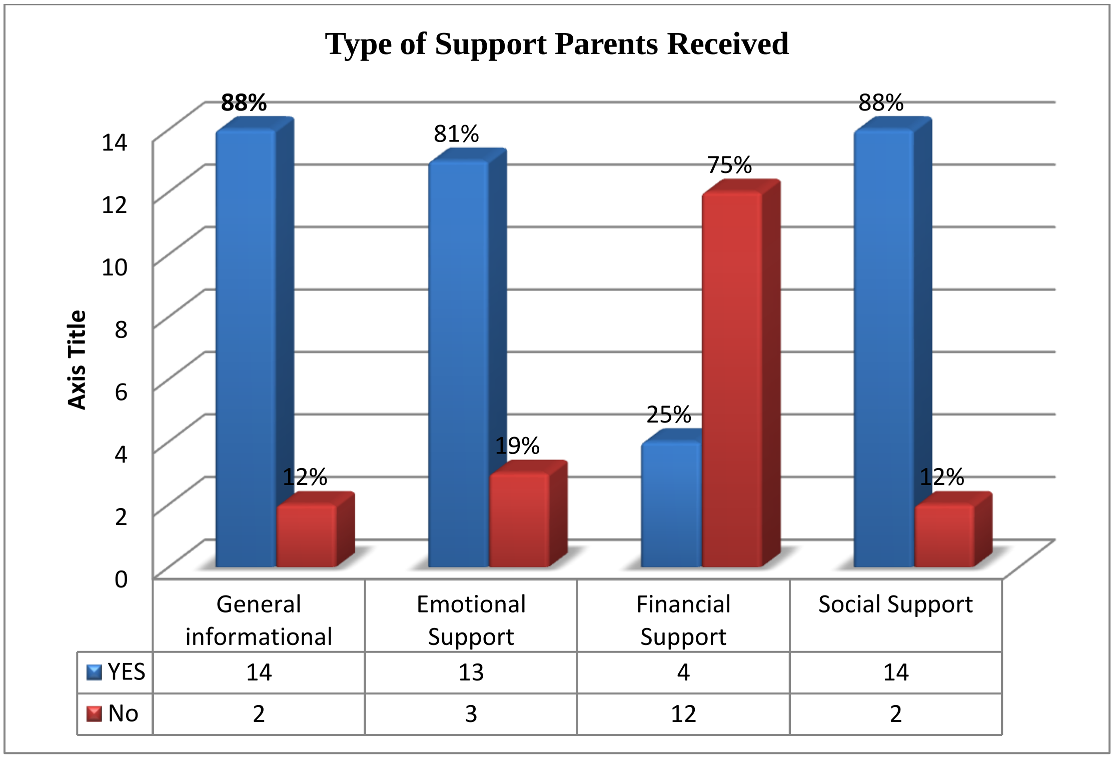
It could be gathered from the above statement that, the most common signs that prompted parents that something was wrong or different with their children was recurrent convulsion, the child's inability to breastfeed for weeks. Unusual physical characteristics and the inability of the children to engage in typical milestone activities expected of children of their age, such as, crying, walking and talking were other signs that got their attention.

After this, parents were asked to indicate the type of support they sought and received when they discovered the exceptionality of their children. Subsequently, parents were asked to describe the nature of the support services they received.

The following types of support guided the interview.

5. Informational supports (knowledge, education, advice, counselling services about a topic of concern with the Intention of providing assistance),
6. Financial assistance (Livelihood support such as LEAP, disability grant),
7. Emotional support, (empathy, trust, caring) and
8. Social support, (tangible aid, material goods, physical work of caregiving).

Figure 3: The Types of Support Parents Received in Support of their Intellectually Disabled Children.



Source**:** Field data (2017)

4.3.1 General Informational Support

From Figure, 4.1 88% of the respondents received general informational support. The parents indicated that, when they discovered the exceptionality of their children in the early ages, they searched for a cure. Many of them further asserted that, they turned to traditional healers, hospitals and religious leaders to search for meaning and cure for their children. Mothers received information support from traditional healers who tried to explain the cause of the children's abnormality as a curse from God. These traditional healers offered them traditional medicine and prescribed sacrifices to be performed to remedy the situation. Parents summarized their experiences;

"I sought help from herbalist when my child was sick, I was told my child was an animal. They asked me to put sand in my room and the next day if my child is a lion, or a snake, any kind of animal, the footprint of that animal will appear on the sand" (Mother of a 14-year-old girl).

"In my search for meaning and cure for my child sickness, a traditional healer told me that when I was pregnant my husband and his friends killed a crocodile from the village river that was why I have given birth to a river child. They told me to go to the river side and leave the child for the river to take her away" (Mother of a 17-year-old girl).

Majority of the parents received informational support in their caregiving situation resulting in their children getting to attend special school for the intellectually challenged in the municipality. A parent narrated that:

"When the child turned three years, a doctor at St. Theresa Hospital invited me to bring my child to the school for the ID children" (Mother of a 15-year-old girl).

It could be gathered from the above statement that, generally, informational support received enabled parents to find helps such as special school in support of their children.

Most of the mothers revealed that, health personnel gave information about the cause, treatment choices and outcomes of the children's condition. A Parent indicated that, a doctor at St. Theresa Hospital always advises her to exercise patience in caring for ID child.

A parent described that:

"When I was delivering they used vacuum machine to pull the child, after delivering, the nurses thought the child was dead, later on the child cried before the nurses knew that the child was alive. The child cried for about three hours before they called doctor to inject her to sleep. The doctor told me that my child had got brain crack because of the vacuum delivery and she would behave like a mad person. She told me that; with time and medication she would be cured" (Mother of a 10-year-old girl).

Parents were enlightened on how to continue the education of their children during vacation at their termly PTA meetings.

A parent expressed that:

"They advised us to be patience with our children and allow them take part in house chores so that they can learn and we also channel our grievances about the caregiving conditions at the school to the school authority" (Mother of an 11-year-old girl).

In their attempt to show care and concern, some community members also provided informational support. This however turned out to be rather destructive as they encouraged parents to get rid of their ID children as a way to liberate themselves from lifelong caregiving stress.

A mother of a 13-year-old girl who is a widow shared her experience:

"While some people advised me and consoled me especially when the child's condition was serious, others told me that my child is not a human being so I should get rid of him especially when my husband died"

4.3.2 Emotional Support

The parents, especially mothers in this study expressed worries, frustration, shame, blame and sadness, which impel some of them to breakdown into tears. However, it could be observed from Figure 3 that emotional support was received by 81% of the respondents. People who care, pitied and expressed empathy about the situation of the parents tried to support parents and caregivers emotionally by consoling and encouraging them not to be dismayed or perturbed. Parents also received this type of support from networks such as PTAs. This usually occurred in the form of sharing of experiences especially during PTA meetings. A Parent explained that:

"The mangers of the PCC and teachers of the school presented to us children who have been able to learn vocational skills and their weaved kente, beads, and school bags at the shelter workshop to encourage us not to lose hope in our children" (Mother of a 12-year-old girl).

The result of the study also indicates that usually some parents drew emotional support from their faith in God by accepting the situation and seeking God's intervention through prayer. Likewise, the emotional support from the preaching and counseling they received from the religious leaders the respondents visited gave them some encouragement.

To this effect two of the respondents indicated that:

I trust in God because only He can console me, I also go to prayer camps for prayers and counselling. I know my child is also a gift from God (Mother of a 15-year-old girl)

It's God who gives, when he gives you good you accept and when it's bad we cannot reject them so with courage I face the condition to care for him (Mother of a 11-year-old boy).

4.3.3 Financial Support

In terms of financial support, only 25% of the parents reported that they received financial support. They asserted that mostly their partners, the disability fund and social protection interventions such as LEAP, NHIS, and feeding grant for special schools, free tuition, and uniform from government were the main sources of financial support.

However, they reported receiving very little financial support from the extended families due to the cultural perceptions prevalent in the area. This situation has made it quite difficult for parents to cater for the ID children. The respondents disclosed during the interviews that, sentiments expressed by the extended families at times escalated the health condition of the children especially when the couples had no money to provide for the child. This meant that, in such instances the onus of providing for the ID child heavily depended on the parents.

A parent recounted her experience in an in-depth interview that:

"The father has been very helpful and has been taking care of the child's education and medical expenses. Apart from him nobody supports me except the support I get from the government" (Mother of a 17-year-old girl).

It could be deduced that, in situations where both parents were present, they tended to bare most of the financial cost in providing for their ID children. On the contrary, widows and single parents asserted that, whether their children went to school or not, ate or not, the responsibility laid on them since they had lost a spouse. More often, mothers are accused of being the cause of their partner's death and the birth of disabled children. These children are perceived as curse and punishment for their evil deeds. Hence, supporting them was said to attract the wrath of the gods. As such they were customarily shun and abandoned by their relatives.

The study revealed that, only 25% of parents reported receiving monies from the disability fund and the LEAP cash transfer. These were parents who were able to register their children with Ghana Society of the Physically Disabled (GSPD) under the GFD. The amount of money received ranged from GH¢ 100.00 to GH¢ 500.00 per annum. An amount which the respondents considered was woefully inadequate. According to the respondents, these monies were seldom paid to them. Thus, making it very cumbersome for them to provide for their children, since some of them had no well-paid jobs. Some of the respondents revealed that, they had received the money only once ever since they registered with the society. Two parents recounted that:

"I registered her with Ghana Federation of the Disability (he brought the membership card) and they supported me with Gh ¢ 500.00 last year" (Father of a 12-year-old girl).

"I received money from the disable association. The first month, I received Gh ¢ 100.00 and recently I received GH¢ 500.00" (Mother of a 17-year-old boy).

In spite of the above, a Mother of a 13-year-old girl expressed her disappointment saying:

"I heard about the help for persons with disabilities. I applied for support for my daughter. After they examined the child's condition, I was told my child's case received

support through the special school but the school authority had not informed me about it" (Mother of a 13 year old girl).

The study discovered that only one respondent received support from LEAP. This was a cash transfer to beneficiaries every month. However, the amount received was GH¢ 56 every two months. A parent related that:

I'm beneficiary of the LEAP programme and I received GH¢ 56 every two months (Mother of an 11-year-old girl).

Additionally, PCC support Parents with livelihood support programme in a form of animal rearing such as goat, and mushroom project. According to respondents because the children cannot do much by themselves, parents had to form parent support groups to undertake mushroom project and goat rearing to support themselves and their children.

The respondents whose children attend the special school also indicated that, government did bear the financial cost of children in the special schools by providing them with accommodation, feeding, school uniform and health insurance for their children. This was considered a form of financial assistance.

Two parents explained that:

"I don't pay school fees except PTA dues of GH¢ 36 every term and my child stays in the school for three months" (Mother of a 12-year-old girl).

"She receives school uniform and lunch at school because she is a day student" (Caregiver of a 15-year-old girl).

4.3.4 Social Support

Finally, social support was one of the support services reported to be received by parents. Indeed, about 88% of them reported receiving support of a social kind largely from their spouses, siblings of the child, and other organizations. This usually came in the form of material, physical, financial, and emotional support translated into physical work of caregiving, assistance with money or clothes, food, encouragement and companionship.

A respondent indicated that:

It's very difficult when school reopens. I struggle buying items on his prospectus. Individuals and my husband help provide for him (Mother of a 15-year-old boy).

It was also gathered that mothers who were fortunate to remain married after having a child with intellectual disability, got their husbands to support them emotionally and socially through the demonstration of care, understanding and acceptance of the child. They also directly encouraged them in their moments of grief.

4.4 The Contribution of Support Services on the Lives of Parents with ID Children.

This objective sought to establish the effects of support services received on the parents. The results are presented in terms of health benefits, emotional benefits, financial benefit, employment opportunities and improvement in social relations. Parents with ID children indicated that, caring for the ID children affected their mental and physical health greatly especially at the initial stage when they discovered the exceptionality of their children and their search for a cure. However, parents noted that the emotional, social, and informational support received helped them enormously to improve their health.

One parent indicated that:

"Because of the initial counselling I had, I have taken it as an assignment given to me by God to take care of her so I don't think about my child's disability too much to affect my health" (Mother of a 13-year-old girl).

Emotional benefits accruing to parents were also indicated. This describes how the reception of support affected parents. The results revealed that, emotional support in a form of advice and encouragement resulted in significant improvements in the lives of parents in their caregiving situation.

A mother shared her experience:

"I took to drinking as a result of giving birth to an ID child. I fell many times into gutters as a result of being intoxicated. But after I received series advice and counselling, today by the grace of God I have stopped all the worries. My attention is now on the health of my child since none of my worries could amend the situation" (Mother of a 14 year old girl).

The trauma of knowing her child's condition ended her in alcoholism. It was the intervention of the support services that drew her attention to focussing rather on the child's health and to stop worrying. She was comforted to forge ahead with her life since very little could be achieved through brooding over the circumstance.

The results on the effects of support services received on work and finances of parents with ID children revealed that, physical support of caregiving positively impacted on work and employment of the parents. Majority of the parents expressed joy and satisfaction in the support provided by the special school. This, they indicated provided them the drive to engage in farming, trading, teaching and other activities freely without thinking about the safety of their children when they are in school.

The above assertion is supported by the following statement from a respondent to;

"I can freely do my daily activities; I can go to work and return anytime." (Mother of a 11 year old girl).

"The school has helped me a lot because if my child was to be in the house, I wouldn't have gone to work today. Whenever she is in the house, I am unable to perform my house chores. But with the help of the school, I can freely work to earn money for the family's upkeep" (Mother of a 15 year old girl)

On social relations, the results revealed that majority of the parents have had some difficulties regarding their relationship with members of their families, friends, neighbours and society in general. Some respondents indicated that stigma still persisted in the form of people despising their children.

To this end, parents recounted that:

"I'm at peace with my neighbours and interact with them freely because my child is not with me now. He fought and beat children in the neighbourhood when he was around. I received a lot of complains every day from my neighbours. He roamed coarsely even into the night. If I didn't sleep with him it's very difficult for him to sleep. But since he went to school I am at peace and my relationship with my neighbours has improved" (Mother of a 16 year old boy).

In addition, a divorced mother had different story to share:

"The father has abandoned us, what will family members do for us. Even it's difficult for people to drink water in my house, my neighbours cane their children because they

played in my house. They drive my child away as if she is an animal when she wants to play with other children in the neighbourhood" (Mother of a 15 year old girl).

4.5 Contribution of Support Services to Intellectually Disabled Children

The final objective of the study sought to discover how the direct and indirect contributions support services to parents trickled down to children with ID. To meet this objective, parents' lives were assessed and their subjective evaluations on the impact of support services on their children's lives were interrogated. The variables in this section included effects of support on children's education (developing of social and vocational skills), health (physical health) and social behaviour (the degree of dependence and display of challenging behaviour of ID children, which include aggression, disruptive, and attention seeking). In addition to assertions by parents, caregivers and key informants on the subject, the researcher also undertook a critical observation of the children's behaviour on the playing field among their peers at home and school

The key informants from the special school in assessing the impact of the support services they provided indicated that, they did not really focus on big things but rather they tended to highlight little things such as putting a smile on the face of the ID children and helping the child to walk and speak. They considered such acts as some of the most important achievements.

A key informant had this to say on the issue:

"We believe that if you make a mentally challenged child to smile, you have made a great impact in his life. If I introduce you to some children in the school, some of these children were isolated; the parent did not allow them to come out. There is one boy here whose

brother lives abroad who built a self-contained house and the child was kept indoors for many years. When the child was enrolled in the school, he defecated anywhere and he could hardly open his eyes. This was because no one taught him how to use the toilet facility in their home. Now he is friendly, happy and toilet trained. Most of them who have speech development difficulties are able to learn "sign language" and when they want to eat or go to toilet, they use the "sign language". The children have been taught life skills and some of them can dress, close the button of their shirts and perform other social skills such as greetings, showing manners and friendliness. They also have Health and safety skills, such as crossing highways and using pedestrian crossing. Academically, some children whose performance was poor at the initial stage have improved dramatically" (Special school Key informant).

Additionally, PCC hand in hand community also appraised the impact of their services on the lives of the abandoned children. A respondent of the community had this to say:
".....yes the effects are well noticed especially our physiotherapy programme. Some of the children couldn't walk but through the physiotherapy Programme and other programmes they have been able to walk and do other things. Some of our programmes may seem unnecessary but with time you will see its impact on the children"(PCC Key informant).

Economically, both key informant from PCC and Shalom Special School expressed that youngsters have become productive members of the society through the vocational skills they have acquired.

"The highest we can talk about is our students at the workshop. At PCC shelter workshop our children are wavering kente, sewing school bags, producing beads for necklace" (Special school Key informant).

"Products made in the Sheltered Workshop are sold in the local shops as well as in Europe. The funds that are generated through the sale of these products are used to support the community" (PCC Key informant).

Socially, parents revealed that since their children attended the special schools they have learned to be more interactive.

Parent recount that:

"Socially, the school has made my child very interactive; she can play with children in the house, she can fetch water on her own, she remembers things they do in the school and practice them during vocations" (Mother of a 10-year-old girl).

A mother narrated that; the behavioural anomaly of her child has reduced although not normal but it is satisfactory. A mother summarized her experience:

"Before she was enrolled in the special school, it was very difficult to control her behaviour of roaming around the community but since she went to the school, she can be controlled. During vacations, when you ask her to sit here or there, she will sit; sit under the tree, she will sit, play with this toy, she will, she informs me when she wants to visit the grandmother then I allow her to go, she doesn't roam about anyhow" (Mother of a 15 year old girl).

However, not all parents reported positive impacts of the services, few mothers expressed being disappointment with the services they rendered. A mother lamented that.

"I have not seen much improvement in his behaviour. He still likes laughing and playing a lot and because he usually beat the children he played with, they are scared to play with him, I am looking forward to seeing a change" (Mother of a 15 year old boy).

Another aspect of support that seemed to have made an impact on the lives of children was in the area of health care services. These services to parents ensured the needed medication and other health needs of their children were catered for. The provision of NHIS cards made it easier for parents and caregivers with ID children to access free health care services at designated health facilities.

A parent narrated that:

"He frequently suffers epileptic seizure and gets injured. I believe that if not for his enrolment I the school, he would have fallen into fire by now. The medication from the doctor has reduced the rate of the epileptic seizure. The school renews his NHIS every year, which enable me to send him to hospital freely" (Mother of a 14 year old boy).

Additionally, the school has put adequate measures to ensure the safety of the children during seizures. A service provider had this to say:

"If a child is attacked by epileptic seizure you will see the child banging the head on the floor so we put soft materials to cushion their head and turn the child sideways because they produce a lot of saliva and have difficulty in breathing" (Special school Key informant).

4.6 Discussions of Results

4.6.1 What are the sources of support available to parents with ID children?

From the data presented that, it was discovered that there were many sources of support available to parents and caregivers of children with ID. These could be described as formal or informal. The principal sources were the State and its agencies, NGOs or CBOs. Some of them were religious agencies and close relatives, siblings and friends.

The Department of Social Welfare and Community Development, among other things, provides services under the auspices of Ghana's Livelihood Empowerment Against Poverty (LEAP) programme in the form of cash transfers to very poor people. The NHIA also provides support in the form of registration of beneficiary children in order for them to access health care free of charge. The various MMDA was also one of the State agencies that provide support to vulnerable people including ID children and their parents. In fact, the Department of Community Development is currently hosted by the MMDAs although their parent Ministry is the Gender, Children and Social Protection Ministry. Lastly, the Department of Social Welfare supervises the disbursement of LEAP and Disability grant to beneficiaries including ID families and other social intervention by the government including registration of health insurance of the disabled community. The Ministries of Health and Education form part of the list of state agencies cited as sources of support for parents with ID children. This is because they performed occasional peripheral duties or services for parents and the ID children.

On the side of non-state actors, religious based NGOs such as the PCC Hand in Hand Community were confirmed to be the key support providers to parents and caregivers. It could be summarised from the results that, the state in collaboration with CBOs, and

NGO's support projects that are geared toward identifying and documenting persons with ID in the municipality. Additionally, the state agencies particularly the department of community development provided funding when available to programmes of CBO's and NGO's relative to ID children.

The finding in this regard is in line with the assertion by Daly et al. (2015) that civil society and the voluntary sector actors in parental support provision provide key services on their own or are usually contracted by government. This finding also affirms World Bank (2004), and NSPS (2008) assertion that, the State has an important role in setting standards, regulating, and providing services to vulnerable groups in the society.

The findings provide evidence of the availability of multiple sources of support for parents with ID children. However, the actual delivery of these services and their impact remain to be evaluated. Indeed, the multiplicity of agencies and institutions involved usually tend to be a hindrance to the speedy execution of decisions to provide support, since a lot of bureaucracy tends to interfere with effective and efficient decision making especially among the state and its allied agencies. There is always the possibility for duplications in efforts since so many institutions are purporting to be doing the same thing within the same space. According to World Bank, (2004), and the NSPS (2008), state funding of responsive formal support services is an important element of policies to enable the full participation of persons with disabilities in social and economic life.

Finally, family members, close friends and relatives, jointly provided some support to parents and caregivers. These were rather informal and usually very difficult to quantify, but proved very invaluable sometimes. Their support came in the form of occasional gifts in kind, cash, spending valuable time with the family and the children and sometimes even saying kind and encouraging words.

4.6.2 What is the nature of Support services?

It is clear from the results that quite a number of support services were available to parents with ID children. These could be grouped into four main ones. The first was general informational support, the second was emotional support and the third was financial support and finally social support. The types of support were inextricably linked to the source it came from. Usually, as confirmed by the parents, informational support included advice and counselling on key issues regarding ID. This came from all manner of persons and institutions, sometimes solicited and at other times even unsolicited.

For instance, the study found that parents received general information and informal counselling while in search of a ‘cure’ for their ID children. They usually relied on advice from a traditional healer, a family member and sometimes from sympathetic community members. These findings are similar to findings of Shin and McDonaugh (2008) that, informal informational support could be provided in the means of advice from friends and family.

The study also revealed that parents sought confirmation or other alternatives of what steps to take from “*divine tellers*”. However, most of the advice they received was based on traditional folk wisdom. The study further revealed that, the *divine tellers* such as the soothsayers, traditionalists and herbalist, Imams and pastors give information on the causes of the children’s abnormality. The respondents indicated that, the divine tellers opine that child abnormality comes as a result of a curse from God or the gods. Based on this assumption, the respondents indicated that, incantations, prayers, traditional medicine and sacrifices were offered especially to the gods in order to pacify them to free the children and the family from any genealogical curse. To the respondents, in order to escape from these curses, at times the deformed child is killed to avert any future curse.

A study by Avoke and Anum (2011), reported that, in some Ghanaian cultures, children with ID are considered as spirit children and such cultures have prescribed ways of getting rid of them. This implies that some of the general informational support extended to parents had traditional understanding of the causes of the disorder and often attributed it to supernatural or religious phenomenon, such as the child being possessed by an evil spirit, the result of an “evil eye”, or a mother’s carelessness in pregnancy. This definitely had implications of care seeking behaviour of the parents and sometimes dire consequences for the wellbeing of the child.

However, the lay or traditional advice was not the only source of information available to parents. In some cases, professional and modern health care advice was received. For instance, a medical practitioner explained to a mother that, brain injury was the course of her child’s condition. This shows that parents received both scientific and traditional informational support.

Finally on informational support, it emerged also that sympathetic community members and health practitioners informed parents about the presence of the Special School for Intellectually Challenged in the municipality where their children could be trained to be independent. This partly contradicts Wang’s, assertion that, ‘following the diagnosis, parents are not taken through counselling and education regarding what to expect, what to do, what services are available to them and where to get help, leaving them to explore the solutions by themselves culminating into stress' (Wang, 2009).

The study revealed that, parents received emotional support in a form of advice and encouragement. Parents together with teachers shared experiences with one another during numerous interactions and engagement. Parents of children with ID also talked to each other, shared experiences and advised each other on how best to cope with their children. This confirms the scenario described by Cutrona (1996) to the effect that emotional support was beneficial when individual received expressions of care, love, and concern from people around them. However, some sympathizers and other members of the community in their attempt to show love and care to the parents and caregiver, ended up suggesting ways to get rid of the children as a means to liberate these parents from lifelong caregiving stress.

In the traditional way, the handicapped child is put along the riverside where these spirits are believed to have their abode. At night, it is believed the spirits, then submerges and takes the child "back home" to the depth of the river with them. This situation portrays the negative cultural perceptions some people have relative to ID children. Thus, the ID children are regarded as a curse, punishment, and shame to their parents, and hence, these children should not be pitied. This view is articulated by Baffoe (2013), who asserts that, children with disabilities are often killed by their families due to negative stereotypes by friends and the members of their community. Although killing the child may shorten the grief of the parents, it is a dilemma that may create confusion or uncertainty for most parents. This study indicated that parents in such a situation often sought spiritual interventions for emotional satisfaction. Thus, parents who resorted to the advice of the gods and were told that the gods had a purpose for their disabled children tended to be quite content with them.

The study revealed that, Parents and caregivers of ID children require extra money to take care of treatment, educational expenses and other material needs of their children. They experience difficulties in meeting basic needs of their children including feeding, medication, and clothing. These result in financial challenges. This is similar to a study by McNally et al., (2013) that reported financial challenges among parents and caregivers of children with disabilities in the Moshi region of Tanzania in meeting necessities like food, clothes, nappies/diapers and shelter and high hospital and transport fees, the results show that parents were largely financially challenged. This situation was particularly dire for the majority of the parents who are low-income earners since subsistence farming, menial jobs, petty trading and carpentry work were their main source of income. This made the seeking and receipt of financial support imperative.

As the results indicate, livelihood empowerment support and social protection intervention such as LEAP cash transfer, although crucial only benefited few parents where an amount of GH¢ 56 every two months was paid to the beneficiaries. This was so because the majority of the parents claimed they had no knowledge of the LEAP programme. The few who knew about it even found the processes of enrolling to receive benefits very cumbersome and stressful. Similarly, the majority of the parents expressed disappointment in the disability fund as well. The few parents who attempted to pursue support from the fund indicated that, they were rejected because their children did not meet the Ghana Society of the Physically Disabled (GSPD) criteria of selecting beneficiaries. GSPD was reported as the vibrant association through which the disability fund was disbursed in the municipality. According to the respondents, the attention that children or people with intellectual disability received was minimal compared to people with physical disability. Accordingly, parents with ID children felt that most of the social interventions available for persons with disability in general tended only to benefit those with physical disabilities to the disadvantage of people with intellectual disability.

In spite of these, some parents were beneficiaries of PCC Livelihood support programme in the form of mushroom project and goat rearing. The proceeds of these support services were shared to support their children upbringing. Although the majority of the parents did not receive direct financial assistance from government, the government's social interventions such as free school uniform, free tuition, and feeding grants provided to their children come without any cost and so in a way government have supported them financially. Most of them indicated that, their financial condition would have worsened if they had to pay for all these services at the special school. The findings were consistent with Redmond and Richardson (2003) to the effect that financial assistance could be provided by the government, to help parents with the potentially increased costs of providing care for an individual with a disability, however most payments are means tested, so not all parents are eligible (Redmond and Richardson, 2003).

Olsson and Hwang's assert that there are free services available to the vulnerable groups and most parents received a monthly grant to compensate for expenses and reduced income caused by caregiving demands. It could be concluded that, formal sources of financial support were available yet majority of the mothers did know where to get the formal sources of financial support. This confirms Villanger (2008) assumption that, cash transfer programmes in Africa usually covered few beneficiaries in a group because of low public sensitization.

The results also show that social support was largely received from the nuclear family. It could be observed that some mothers who were fortunate to remain married after bringing forth a child with intellectual disability, received support from their husbands both emotionally and financially. This could be deduced from the man's understanding behavior and acceptance of their children and directly encouraging their wives in those moments of grief. Similarly, Divan et al., (2012) reported how a husband transformed from a quarrelsome, unreligious social drinker to a God-fearing man as the couple sought religious sustenance following the birth of the child with intellectual challenge (Divan et al., 2012).

However, there was low social support for widows and single parents from their extended family. The extended family failed to support parents with ID children usually because they considered them a bad omen to the family and the society as a whole. Corresponding studies have shown varied reactions from extended families with only few mothers getting extended family support (Anum, 2011; Edwardraj et al., 2010; John, 2012). It is therefore not surprising that, some family members particularly the extended family asked parents to get rid of their ID children.

The result of this study demonstrates that parents received social support in a form of caregiving from the special school. The caregivers and teachers were often confronted with the need to provide care for the children's physical needs and dealing with excessive demands of caregiving which included bathing, feeding, brushing, dressing and giving medication. Parents attend to their children's physical needs only when the children are on vacations.

In addition, siblings often helped to care for the children especially while mothers were away. This is similar to a qualitative study by Dyson (2010) and John (2012) that, siblings (especially female siblings) sometimes assumed responsibility of protecting and caring for their sibling with ID. This eases the mother's daily stress and experience of physical difficulties. Material supports received were in the form of provisions, assorted drinks and biscuits usually during Christmas. Others received donations from philanthropist and other individual who cared for the children.

However, the study discovered that although social support emanated largely from family and other close relatives, some fathers found it tough to support the physical needs of the children since they scarcely stayed in the house. Non-Governmental Organizations, charitable organizations and sometimes individuals supported the parents in providing wheelchairs, food and sometimes assist in paying treatment bills as noted by Gona et al., (2011). This confirms the assertion by Cutrona, (996) that, that tangible support occurs when someone provides material goods or assistance to aid another.

4.6.3 What are the Effects of Support Services to Parents?

The social, informational and emotional supports received had positive impacts on parent's mental health through the enlightenment on the children's condition. It was found that, when parents had reduced burden and hardship, it positively affected their physical health. This was possible when children spent most of their days in school and only come home during vacations. Parents had improved mental health conditions when they attribute their children's condition to acts of God. Mothers who reported physical health complications like hypertension, headaches and waste pains however did not directly attribute them wholly to the effects of the caregiving but partly blamed their farming activities and aging. The implications are that, if parents have improved quality of life, mental health and wellbeing, it is also possible that the benefits will be transferred to that of their children (Majnemer, Shevell, Rosenbaum, Law, and Poulin, 2007).

Parents especially mothers expressed worries, frustrations, and sadness regarding the predicament of their children. This impelled some of them to turn to the abuse of alcohol and regularly breakdown in tears. However, parent's religious faith, prayers and counseling by religious persons provided them some emotional strength, hope and support in dealing with the provoking feeling of disappointment and heartbreak. The study discovered that, after such sessions with religious personalities, parents and caregivers become optimistic of what the future held for their children. To some extent, this increased parents and caregivers level of attention and affection for the children leading to acceptance, and reduced emotional stress. This corroborates the findings of Peer and Hillman (2012), who posited that having an optimistic personal disposition helps parents to avoid associated caregiving stress by dwelling on benefit and joy of having an ID child. This also conforms to the views from elsewhere that when parents lean on their religious beliefs, they tend to perceive the child's disability as a gift from God and a trial of faith, thereby developing a positive attitude and reduced emotional stress (Gona et al., 2011).

This implies that parents have emotional stability amidst religious and cultural believe surrounding their children. Informal counseling led to relieve of the feelings of guilt from accusations emanating from the society; it also enhanced parents' capacity such as patience and their propensity to spend time to care for their children during vacations. This also strengthened parent of ID children's feeling of connectedness to each other through sharing of experiences. Similarly, Turnball, Blue-Banning, Turbiville, and Park (1999) reported that, Parent-to-parent connection has been shown to positively affect the physical and emotional wellbeing of both parents and children.

The study revealed that, the supports received affected parents work positively in the sense that mothers had reduced burden regarding where to leave their children during working hours after they enrolled their children in the special school. Additionally, siblings also supported parents in providing care especially while mothers were away. With the exception of a few mothers, majority of the respondents articulated that, they had free time to engage in their daily activities as a result of the support they received from others. Therefore, it was expected that parents' ability to work would improve their economic status.

Bourke-Taylor et al., (2010) reported that, mothers of ID children have reduced opportunity to work or stopped working because they are preoccupied with meeting the needs of their children. The study found that most of the mothers relied on farming and their partners as sources of income yet the financial demands of caregiving exceeded the income obtained from their work. According to McNally et al., (2013), financial constraints among parents and caregivers of children with disabilities make it difficult for parents to provide basic necessities like food, clothes, nappies/diapers, shelter and high hospital and transport fees for their children. As has been articulated already although only few respondents benefitted from the LEAP and disability grants, they invested the money in small-scale enterprises such as trading and this improved their livelihood. This confirms Villanger (2008) that cash transfer programmes in Africa usually covered few beneficiaries in a group.

Another key effect of support services to parents was in the area of social interaction and relations with their neighbours. The study revealed that, majority of the parents didn't have many difficulties regarding their interaction with families, friends, neighbours and society in general. People had become more amenable with them owing to the amount of public sensitization. Parents noted that discrimination and stigmatization of their children was gradually reducing since their children started schooling. They added that, now they could attend and participate in social gatherings. In consonance with this, caregivers at the special school validated this assertion and emphasized that, they enjoy the company of the children and took them to religious programmes without any stigmatization and discrimination from the public.

However, some mothers indicated that stigma still persisted with people making mockery of their children by laughing and staring at them because of the uncooperative behaviour that the children exhibits. Again, there was the tendency of parents with ID children to form a bond by confiding in each other and sharing experiences. This improved their social relations and helped them to cope with their predicament in a better way. This affirms findings by Konrad (2007) that access to a confiding and nurturing relationship through a one-on-one connection can be a bridging experience for parents with a newly diagnosed child.

4.6.4 What are the Effects of Support Services to Children?

The study revealed that, education and training of the ID children received significant attention in the municipality. PCC hand in hand community and Shalom Special School effectiveness of special education was a success in helping students with disabilities to maximize their potential and environment. Their education focused on social and community living skills which is structured around five domains that represent the person as he or she lives, works, plays and moves through the community. This was evident as children could express greetings, showing manners, friendliness, use pedestrian crossing, and communicate with sign language. The most perceptible contributions of the educational support was evidenced in the fact that the children were able to learn vocation skills such as weaving, bead making, sewing and other handiwork at PCC shelter workshop to secure their future and earn a living. Results of the study revealed that the school helped IDs to acquire some pre-vocational skills that will helped them to acquire vocation in weaving, beads making or in animal rearing. It was revealed that caregivers ensured the safety of the children and were responsible for meeting their physical needs in the school during the term. Special teachers play dual role; they are educators and parents. They therefore, show sympathy to their students (Alderman, 1990; Mercer and Mercer, 1998).

As a result of the effectiveness of the school’s programme towards social skills development, some children with mild and moderate intellectual disability found themselves functional in their communities contributing to development. Scheerenberger (1983) emphasized that, special schools were the most appropriate for the mentally retarded because they have active education and training programmes. Parents seemed to expect more from the special school in improving the independence of their children. Some parents were optimistic that their children would one day be able to live independently and engage in a job. Mothers’ optimistic expectation could also be related to the severity of their children's disability because some of the children are totally dependent and had very low IQs, which affected their ability to learn or master basic skills. This conforms a study by Schalock, et al., (2007), which asserted that children with intellectual disability experienced substantial limitations in their intellectual and functional abilities, which obstruct their social, practical and personal life skills (Schalock, et al., 2007). According to Hallahan and Kauffinan (1994), the functioning of virtually, all people with mental retardation can be improved and that those with mild and moderate conditions can improve their social skills competence to the point that they are no longer classified as disabled when given the right placement and relevant programmes.

Similarly, it was revered that children could now perform some daily activities independently. It was not surprising that the researcher spotted few children washing and cleaning their dormitories at the special school. Similarly, parents described their children's post support experience as calm, not roaming and able to intermingle with other children in the neighborhood. However, only few mothers were doubtful that the special school could train their children to control their aggressive behaviour of beating of children they played with.

The health of the ID child was an essential area which was of concern to both parents and other stakeholders. This was never neglected even in the midst of challenges in caring for the children. Children at the special school are regularly, assessed by a team of specialist on their intellectual functioning and per the assessment given referrals or recommendations for the child's enrolment into the special school. This corroborates the assumption of Mandel and Fiscus (1981) that children suspected of having learning problems should be given thorough and holistic assessment through the use of formal and informal strategies. It was revealed that children who had epilepsy were on medication. This means that, despite financial difficulties in providing their children's basic needs, parents whose children were epileptic were guaranteed a regular and timely supply of drugs when they were at the school.

Additionally, caregivers ensured adequate nutritious food to keep the children healthy and also administered the drugs of the children religiously according to doctor's prescription. It emerged that in spite of the drugs, some children still experienced aggressive and mild epileptic seizures. Therefore attending to the child and using soft material to cushion the head of the child were some of the safety measures put in place to preclude them from self-injury during seizure. Even though, children with ID tended to suffer from a series of health complications, it was realized that most of them were generally healthy.

CHAPTER FIVE

SUMMARY, CONCLUSION AND RECOMMENDATION

5.0 Introduction

This chapter presents the summary, conclusions and recommendations of the research findings. The study investigated the sources, types, and nature of support services and their contributions on the lives of parents and ID children in Nkoranza south municipality.

5.1 Summary of Findings

On the sources of support for parents with ID children, the study found out that the Department of Social Welfare and Community Development played a key role in managing and coordinating government's programmes for the vulnerable, which includes District Assembly Common Fund for Persons with Disabilities, LEAP, free registration and renewal of their health insurance among others. The Department provided these interventions in collaboration with other bodies like the Ghana Federation of the Disable (GFD) and the PCC- Hand in Hand Community.

Another source of support recognized was the Shalom Special School for the Intellectually Disabled, which supported parents in training and educating ID children. The support included skills training geared toward the acquisition of some vocational skills in weaving, bead making and animal rearing. Besides this, the government provided assistance such as feeding grant, free tuition and free school uniforms.

The study also found that Non-Governmental Organization like Peace of Christ Foundation provided a residential Community for abandoned and intellectually disabled children. The Community provided services such as, physiotherapy, hydrotherapy, shelter workshops, day care, summer school, and speech programme to children with multiple disabilities. They also supported parents with livelihood intervention programmes. Finally, other sources of social support included families, neighbours, religious leaders, health practitioners, individuals and community members.

In dealing with the challenges they faced while taking care of their ID children, parents and caregivers received general information and informal counseling. They relied on advice from traditional healers, medical practitioners, family members and sometimes from sympathetic community members after learning about their children's exceptionality.

The study also found that, parents received varied emotional support in a form of advice and encouragement. Parents together with teachers talked to each other, shared experiences, encouraged and advised each other on how best to cope with the children. Parents further depended on their faith in God by accepting the situation and seeking God's intervention through prayer. Other members of the community in an attempt to show love and care for the parents, suggested ways of geting rid of the children to liberate themselves from lifelong caregiving stress.

In terms of financial support, the study discovered that direct cash transfers from LEAP and the Disability Fund was enjoyed by very few parents and caregivers. However, the

PCC supported parents with livelihood support programmes in a form of animal rearing and mushroom production projects which yielded some direct financial earnings. The study also found that parents considered the feeding grant, free tuition, free NHIS registration, and free school uniform received by their children as indirect financial assistance that eased their financial burden.

The study revealed that, social support was largely received by the parents from their spouse, siblings of the child, and other organisations which provided material, physical, and emotional support mostly in the form of helping with physical work of caregiving, assistance with money or clothes, food, and encouragement. Husbands supported wives by their acceptance of the child, paying for school and medical expenses whiles siblings helped in physical work of caregiving. This affirms Howie-Davies and McKenzie (2007) that support from immediate families and friends are essential to assist parents who have a child with disabilities. The caregivers at the special school supported parents in caring for the children's physical needs in a form of training the child to be able to perform basic daily life skills and vocational skills independently.

The study found that social, informational and emotional support received in the form of advice and encouragement enlightened parents understanding of their children's disability. This eventually enabled them to provide the necessary assistance that the children required. It was also found that mothers had reduced burden and hardship, which positively affected their physical and mental health after they had enrolled their children in the special school.

The study revealed that, emotional support in a form of advice and encouragement received brought significant improvement in the lives of parents in their caregiving situation. This is because their faith, prayers and counseling by religious leaders provided them emotional strength, hope and nourishment in dealing with provoking feeling of disappointment and heartbreak. The study further found that, parents who received informal counseling from medical practitioners were relieved from the feeling of guilt. This further empowered them to withstand suggestions to get rid of the children to liberate themselves from lifelong caregiving stress.

The study found that, work and employment of the parents saw a positive turn around. This was because they could now engage in their daily activities freely without worrying about the safety and where to leave their children during working hours after the children had been enrolled into the special school. This obviously reflected positively on their financial situation.

Another interesting finding was that, majority of the parents had reduced difficulties regarding their interaction with families, friends and neighbours and society in general. Parents recounted that they were at peace with their neighbours because their children were now in school and caused no troubles in the neighborhood. Siblings and partners understanding and acceptance of the children’s disability showed the warm relationship within the nuclear family. This significantly affected mothers positively to be resilient in their situation. The advocacy programmes by PCC and shalom special school influenced the cultural perception on the populace to become more receptive towards them. However, some divorced mothers and widows still experienced some form of negative social relations from their neighbours as a result of uncooperative behaviour that the children exhibited and the absence of their husbands.

On the effects of support on ID children, the study found that, the special education provided by the School and Community, proved to be a success since it was helping students with disabilities to maximize their potential. Through social and community living skills training, the children could offer and respond to greetings, show good manners, be friendly, successfully use pedestrian crossing, and communicate with sign language.

Another finding with regards to ID children was that, the PCC shelter workshop equipped children with vocation skills such as weaving, beadwork, sewing and artwork to earn a living.

The study found that parents appreciated the effects of the special school on their children social behavior. It was also found that to some extent their children could perform some activities of daily living independently. They described the children as calm and not roaming as they use to do. However, few mothers with unmet expectations were hopeful that the special school will train the children to control their aggressive behaviour of beating their playmates.

It was revealed that the health of the ID children was adequately catered for. Children on admission at the special school got a regular and timely supply of drugs. Additionally, caregivers ensured the adequate provision of nutritious food to keep the children healthy. Also, caregivers administered drugs to epileptic children religiously according to doctor's prescription. Hence, the health status of the children was generally good.

5.2 Conclusion

It is an established fact that parents caring for children with ID go through hardships including physical, emotional, social, financial, and work difficulties.

Parents in dealing with the challenge of caring for ID children received support from families, neighbours, religious leaders, health practitioners individuals, community members, and non-governmental organisations, The findings provides evidence of the availability of multiple sources of support for parents with ID children. However, the actual delivery of these services and their impact remains to be evaluated. Indeed, the multiplicity of agencies and institutions involved usually tend to be a hindrance to the speedy execution of decisions to provide support. There bureaucratic process involved tends to interfere with effective and efficient decision making especially among the state and its allied agencies. There is always room for duplications in efforts since so many institutions are purporting to be doing the same thing within the same space.

The study largely corroborated the appraisal perspective of the stress and coping theory. The theory predicts that belief in the available support influences parents appraisals of stressful situations of having and caring for ID children.. Therefore, support services as buffering, influenced parents' positive appraisal of their health, emotions, work, employment, finances and social relation.

Additionally, most of the findings of the study were consistent with social ecological understanding of disability which does not focus on curing a person. Rather, what needs to be "cured" is the context in which the person functions. Therefore, informational, emotional, financial and social support parents received from various support providers effectively bridge the gap between parents, ID children and the environment.

5.3 Recommendations

The following recommendations have been made based on the findings of the study to the following bodies and institutions.

Ministry of Health (MoH)

The ministry of health should carry out screening exercises to identify children with ID for early intervention. The ministry should intensify education of the public through the media on the causes of ID to eradicate stigma and discrimination. The ministry should ensure training of specialists in ID care, and formal counseling of parents to reduce parental burnout.

Ministry of Education (MoE)

The ministry of education should critically appraise the existing special schools and ensure that they are adequately resourced to benefit the children and in effect, their parents as well. Additionally, the ministry should collaborate with NGOs to equip the special schools with vocational training workshops, adequate trained personnel, teaching and learning resources to help them to be self-employed in future.

Department of Social welfare and community development

The department of social welfare should collaborate with the MOGCSP, MMDA, NCPD, GFD and NGOs and lobby government to increase the quota of the District Assembly Common Fund allocated to PWDs. The current 2% should as much as possible be increased. This is because the disability community is increasing with a corresponding increase in the application for the fund. The department should ensure timely release of the District Assembly Common Fund for persons with disability.

Effort should be made to amend the LEAP intervention criteria of selection of beneficiaries to include intellectually disabled children irrespective of the economic status of their community.

The parents

The Department Of Social Welfare recommend that, parents should come together to form mother-to mother-support groups that will stand independent and be classified under Ghana Federation of the Disabled with the tagged: Parent Association of Children with Intellectual Disability to support each other and also advocate for their children. Special school teachers also recommend that parents should continue the training of their children during vacation since they are partners in effective education of the children. Parent should ensure early diagnosis and support to ensure effective development of their ID children.

The General Public

The public should avoid discrimination or stigmatization of people with ID or their families and Support people with ID to live normal lives.

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APPENDICES

INTERVIEW GUIDE

UNIVERSITYN FOR DEVELOPMENT FOR STUDIES
FACULTY OF INTERGRATED DEVELOPMENT STUDIES
DEPARTMENT OF OF SOCIAL, POLITICAL AND HISTORICAL STUDIES

INFORM CONSENT FORM

The purpose of this interview is to examine the effects of support services on parents with intellectually disabled children in Nkoranza South Municipality. This research is in partial fulfillment of the requirement for the award of master of philosophy degree in social administration. you are assured that the data collected is strictly meant for academic work and would be treated with outmost concealment.

The above document describing the benefits, risks and procedures for the research title **"Effect of Support Services on families with intellectually disabled children in Nkoranza South Municipality"** has been read and explained to me. I have been given an opportunity to have any questions about the research answered to my satisfaction. I agree to participate as a volunteer.

______________ _______________________

Date Name and signature or thumb print

Interview Guide.

Section A: Demographic Information

1. Sex ___
   - Male ☐
   - Female ☐

2. How old are you? ____

- 15 -19 ☐
- 20-24 ☐
- 25-29 ☐
- 30-34 ☐
- 35-39 ☐
- 40-44 ☐
- 45-50 ☐
- 50 + ☐

3. What is your level of educational? __________

Education

- Tertiary ☐
- SSS/Middle School ☐
- JHS ☐
- Primary ☐
- None ☐

4. Are you married? ____

Marital status

- Married ☐
- Single ☐
- Widow/ widower ☐
- Divorce ☐
- Co-habitation ☐

5. What work do you do? ___

Employment status

Formal employment
specify____

Informal employment
specify____

8. How many children do you have? ___________________________

9. How many of them have ID_____________________________

10. How old is your child with disability__________________________

11. What is your Relationship to the child? ____________________

Biological ☐
Caregiver ☐

Section B: Guiding Question

INTERVIEW GUIDE FOR PARENTS WITH ID CHILDREN

Please reflect on their initial experiences when you realized you have given birth to an intellectually disabled child.

Type and Nature of Support Services available to Parents with ID Children

Do you receive the following types of support?

	Types of support services	Yes	No
1	Do you receive Informational supports (knowledge, education or advice)		
2	Counseling Services?		
3	DO you receive financial assistance		
4	Livelihood support such as LEAP?		
5	Disability grant for your child?		
6	Do you receive Emotional support, (empathy, trust, caring)		
7	Do you receive social support, (tangible aid, material goods actions that help a person feel connected)		

- Describe the nature of the received support in regards to the caregiver's situation

____

____

➢ Probe question for support network
- One-on-one mentorship,
- community-based parent networks,
- technology-enabled parent networks,
- and peer support groups

- **Section C: Guiding Question**

2. **Sources of the support services to parents with ID children**

- Where are the sources of these support services?

____

____

➢ **Probe**
- ○ Religious bodies

- Individuals / families
- Community based organisations (CBO's)
- NGO's
- Government agencies. (e.g. Social welfare)

Section D: Guiding Question

3. Impact of support on Challenges in caring for intellectually challenged child (outcome)

- How does the support services received affect your life as a mother of ID child?

____

____

____

- Probe; socially, economically, financially emotionally and health,

- How does the support service received affect the life of your ID child?

____

____

Probe; socially, education, child behaviour, and health

Section E: Guiding Question

INTERVIEW GUIDE FOR SERVICES PROVIDERS

- Describe your organization

____

____

- Probe: history, mission, vision and core activities

____

____

- Specify the support services the organization provides to parents with ID children.

____

____

- Explain the motives of providing these support services to the parents and their ID children

____

____

- What are the impact of these social services in the life of parents and their ID children

____

____

- What are the challenges in providing these services

____

- Suggest ways to improve support services delivered to parents with ID children.