### KWAME NKRUMAH UNIVERSITY OF SCIENCE AND TECHNOLOGY **KUMASI, GHANA**

In partial fulfillment of the requirements for the degree of **Master of Science** 

(Disability, Rehabilitation and **Development**)

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Assessment of the capacity of health facilities in the early detection of disabilities in children in the Brong Ahafo Region of Ghana

 $\mathbf{BY}$ 

Joseph Baba Yinbil

PG NO. 3827309

FEBRUARYNOVEMBER, <del>2015</del>2016

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A Thesis submitted to the Department of Community Health, **College of Health Sciences** 

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COLLEGE OF HEALTH SCIENCES

SCHOOL OF MEDICAL SCIENCES

DEPARTMENT OF COMMUNITY HEALTH



EARLY DETECTION OF CHILDHOOD DISABILITIES IN THE BRONG
AHAFO REGION OF GHANA: AN ASSESSMENT OF THE CAPACITY OF
HEALTH FACILITIES.

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and duly acknowledged, this project report presented to the Community Health	
Department of the Kwame Nkrumah University of Science and Technology, Kumasi,	
Ghana, for the award of Masters of Science degree in Disability, Rehabilitation and	
Development, is the result of my own original investigation and that no part of it either in	
whole or part has been presented for another degree in this University or elsewhere.	
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Advances in medical technology have improved on the health of many infants who have sustained injuries during intrauterine development or birth, giving them a better chance of improved quality of life. Nevertheless, some conditions still create overwhelming consequences causing lifelong disabilities. Many infants injured during the birth process or born with congenital anomalies have long term effects from their conditions. Their families may have long-term effects as well. There is therefore the need for early detection and prevention measures to curb the incidence of disabilities in newborns. This study is therefore aimed at assessing the capacity of health facilities to facilitate the early detection and intervention of disabilities in infants and children in order to prevent the debilitating effects of such disabilities on children.

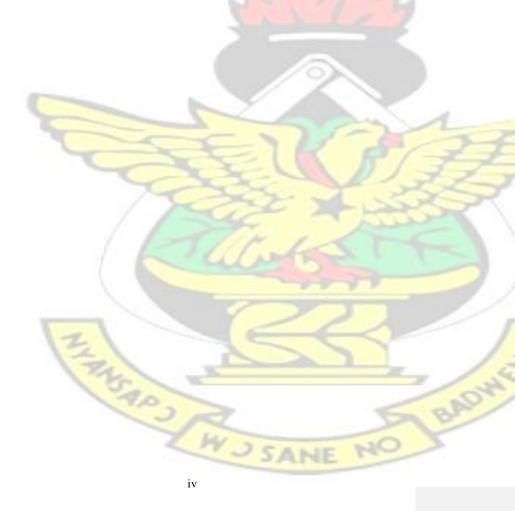
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Findings confirmed that Pediatricians, midwives and other health professionals employed various techniques including physical examination or assessment to determine if they have any defect.

They did this by listening to the cry of the newborn child, the color of the eye, the physical appearance of the baby, and the color of the skin. The findings of the study indicated that most of these examinations were conducted between the first hour and 48 hours after birth and detection usually occurred during this examination period. The results of the study also

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showed that most of the facilities lacked modern screening equipment. To improve on the effectiveness of health facilities to detect disabilities in newborns and infants, there is need to create a unit for early detection and treatment of disabilities in every health facility, provide enough screening tools and modern equipment for every unit/facility, and pregnant women should be encouraged to take antenatal care seriously.



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DEDICATION

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This research work is dedicated to my life partner, Linda and my kids Jayden, Emma and Annie.

I love you all.

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I acknowledge the contribution of my supervisor Dr. Wisdom Kwadwo Mprah in making this work take shape. His diligence and attention to detail is what actually made this project a reality. God bless you.

I am also indebted to Dr Anthony K Edusei who encouraged and spurred me on when i encountered some challenges. God bless you.

I also acknowledge the various authors whose works I extracted information from for this study.

Last but not the least I thank all respondents especially the heads of the various health facilities I selected for my study.

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#### INTRODUCTION

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#### 1.0 BACKGROUND TO THE STUDY

Although the health delivery system in some developing countries has gradually improved over the years, a lot of questions still arise concerning the capacity of the various health facilities such as hospitals, clinics, and maternity homes to facilitate the early detection of "abnormal" conditions in children to avert permanent disabilities in future (Cole & Flexer, 2007). Health facilities can effectively perform this function if the referral system is effective and they are well equipped with the appropriate resources such as skilled health personnel who can perform screening in newborns and children, screening equipment/tools, and funds (Cole & Flexer, 2007).

Another important consideration for screening for early detection of potential disabilities in children is the time frame. It is vital that "abnormalities" are detected early enough so that measures can be taken to prevent permanent disabilities. The early years of infants are very critical especially to developing language and communication since it is the time when the brain is at its highest capacity of development and undergoes some structural changes in response to external stimulation (Cole & Flexer, 2007).

The American Academy of Paediatrics (AAP) (2002), states in its policy document that, early identification of developmental disorders is critical to the well-being of children and their families. It is the function of the primary health care and the responsibility of all pediatric health care professionals. Hence, screening newborns does not only leads to children benefiting from treatment but also give access to support and services that can lead to various profits to the child and the families.

Studies have revealed that the rate of current developmental disorders detection rates are lesser than their real prevalence in developing countries, this implies that the numerous setback to identifying developmental disorders among children are not yet overcome especially in health facilities in non-industrialized countries (AAP, 2002).

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The availability of appropriate assessment tools for screening newborns could increase the effectiveness of health facilities to detect disabilities in newborns. For instance, at the birth of every child at hospitals and other health facilities, an Apgar assessment is administered to the child one minute after birth or delivery and again after five minutes, to ascertain the likelihood of the neonate developing disabilities. It involves examining the heart rate, reflex irritability (by facial expression), muscle tone, breathing and skin colour. The Brazelton's (1990) Neonatal Behavioral Assessment Scale is also a popular assessment tool that is valuable in the assessment of newborns for need of special care.

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Pediatricians and midwives and other health professionals employ physical examination to conduct assessment on the newborn child to see if the child has a defect or not. They do this by listening to the cry of the new born child, observing the color of the eye, its physical appearance and the color of the skin. Through these assessments they are able to identify whether or not a child has a disability or is likely to develop a disability (Boyle CA et al., 2005).

It is also worth noting that screening of infants and children for disabilities encounter myriad of challenges which can make its full implementation difficult if not impossible. Challenges, such as, lack of highly accurate screening tests, high cost and unaffordable screening tests, inequities in access to expanded screening, absence of a voluntary system

of screening with informed consent, and inadequate systems of follow-up and support for families, are but some of the challenges (Boyle CA et al., 2005).

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These notwithstanding, the benefits of the concept of primary health care screening for neonatal disabilities will outweigh the negatives if well embraced. So if infant and child screening is worth doing, it has to be done well (Boyle CA et al., 2005).

#### 1.1 PROBLEM STATEMENT

It is estimated that about 15% of the world's population live with some form of disability, of which 2-4% experience significant functional difficulties (World Health Organisation (WHO), 2012). Approximately 80 percent of Persons with disability live in low-income countries (Ayiku, 2012). According to the same report, at least 81,200,000 people affected by some form of disability live in Africa (10%). The report further states that 75% - 80% of persons with disabilities in the Region of Africa are found within the rural areas, which have no or limited rehabilitation and prevention services.

Globally, there is a projected increase in the number of children with disabilities, particularly in developing countries, due to factors such as malnutrition, diseases, child labor, armed conflict and violence (Boyle and Cordero, 2005). For instance, about 3% of children born in the United States suffer a major birth defect with birth defects accounting for about 20% of all infant deaths. About 17% of children in the United States are said to have developmental disabilities, with about 2% having a disabilities severe enough to require life-long care and special services (Boyle and Cordero, 2005).

Disability is becoming a major problem in Ghana. Although statistics on disability in Ghana especially on children, is difficult to obtain, the 2010 population and housing

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census estimates that 3 percent (737,743) of Ghanaians were living with one form of disability or the other with visual impairment being the highest. The prevalence rate of disability in Ghana generally increases with age. The disability prevalence rate increases from 1.4 percent at age group 0–14 years to 3.1 percent for those aged 15–64 years then to 14 percent at age 65+ years (Ghana Statistical Services (GSS), 2012). It is estimated that, there were 54,038 persons with disabilities in the Brong Ahafo region. This constitutes 2.3 percent of the population for the region (GSS, 2012).

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In a study conducted by the United Nations International Children's Emergency Fund (UNICEF) in 18 low and middle income countries including Ghana, 23% of children aged 2–9 years screened positive for disability in the 18 participating countries. In Ghana it was found that of a total 5,391 children screened, 21 % were positive for disability (Gottlieb et al., 2006).

However, despite the rising interest in child disability, little is known about the frequency and situation of children with disabilities in countries with low and middle incomes (Grantham-McGregor et al., 2007). Although there is no accurate data on the prevalence rate for children with disabilities in Ghana, conditions in Ghana would likely cause an increase in the prevalence rate.

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The question that arises is whether the health facilities in Ghana are prepared and capable of conducting screening of infants and children for the early detection of impairments for prompt intervention (anonymous). Without the needed facilities and equipment for early detection and prevention, there is likely to be an increase in the prevalence of disability

among children in Ghana. In order to curtail this, early detection measures would have to be instituted and promoted in health facilities in Ghana.

This study therefore aims at assessing the capacity of health facilities to facilitate the early detection of disabilities in neonates and children for early intervention in order to reduce the impact on the developing competencies of children.

#### 1.2 RESEARCH QUESTIONS

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- 1. What are the practices applied in health facilities for the early detection of disabilities in neonates and children?
- 2. What are the resources (skilled personnel, technologies/equipment, and funding) at the disposal of institutions in the early detection of disabilities in neonates and children?
- 3. What are the challenges faced by health facilities and the personnel in the early detection of disabilities in children?

#### 1.3 GENERAL OBJECTIVE

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The main objective of the study is to assess the capacity of health facilities for the early detection of disabilities in children.

#### 1.4 SPECIFIC OBJECTIVES

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- To identify the existing practices with respect to the detection of disabilities in neonates and children.
- To identify and assess the resources (skilled personnel, technologies/ equipment, and funding) at the disposal of institutions for early detection of disabilities in neonates and children

3. To examine the challenges faced by the various health personnel and health facilities in screening for early detection of disabilities in neonates and children.

#### 1.5 SIGNIFICANCE OF THE STUDY

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The study will provide empirical data on existing practices or procedures in health facilities across the Brong Ahafo Region of Ghana regarding the early detection of disabilities in children for early intervention. The study also seeks to identify the existing resources (technological, skilled personnel, and funds) and challenges that impact negatively on the ability of health facilities to undertake early detection of disabilities in children. The study will therefore provide information on the capacities of these health facilities and the challenges they face in order for the appropriate authorities to take measures to improve upon their capacity for early detection of disabilities in children. Based on the findings, recommendations will be made to appropriate authorities to encourage a compulsory nationwide programme for screening of all newborns and children at health facilities for early detection of impairments and disabilities for early intervention.

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Finally, the study report will be used as material for reference mostly to students and people who are interested in issues concerning disability (especially early detection and intervention in childhood disabilities) for further research in this area.

#### 1.6 ASSUMPTION OF THE STUDY

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The assumption of the study is that health facilities/hospitals within the Brong Ahafo Region of Ghana do not have the capacity to facilitate the early detection of all forms of disabilities in children for prompt intervention.

#### 1.7 LIMITATION OF THE STUDY Formatted: Font color: Auto

The study was limited to medical directors, nursing administrators, medical officers, nurses and midwives in the maternity, labour and paediatric wards, paediatricians and biomedical scientists/laboratory technologists of selected hospitals in the Brong Ahafo Region. The study did not involve other health personnel who are not in management positions or do not directly care for newborns or children in the selected health facilities.

## 1.8 CONCEPTUAL FRAMEWORK

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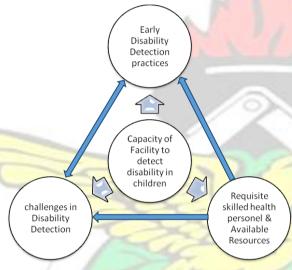


Figure 1: Conceptual Framework

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#### **Explanation of the Conceptual Framework**

The capacity of a health facility to promote the early detection of disabilities in children-

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has

a direct correlation with the availability of the requisite skilled health personnel who are well trained. Appropriate early detection practices such as screening, thorough

physical examination, and the use of the Apgar score will facilitate the early detection of disabilities in infants and children.

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For these professionals to execute the task of early identification of disabilities in children within a reasonable time frame, they need to have the requisite screening tools and equipment. Also, for the sustenance of an effective screening programme, the health facility needs regular source of funds. The time frame within which disabilities can be detected by these health personnel is also directly linked to the challenges they face in the course of undertaking the screening of newborns for disabilities.

#### 1.9 STRUCTURE OF THE STUDY

The study have six chapters. The first chapter, presents the study and also outlines the statement of the problem, and states the rationale for the study. In this same chapter, the study's questions and objectives and the delimitations are also spelt out.

The second chapter presents literature related to the capacity of health facilities to ensure early detection of disabilities in children under the following areas: practices/screening procedures for the detection of disabilities in children, personnel responsible for detection of disabilities in children, resources/technologies for early detection of disabilities in children, and challenges faced by health facilities and health personnel in detecting disabilities in children.

The study methodology is captured in chapter three, it entails the study population, research design, the sampling technique employed and sample size, the research instruments as well as the method used in collecting the data, data analysis, pretesting of data collection tools and the ethical considerations.

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Chapter four presents the study findings, while Chapter five presents the discussions of the findings. The final chapter, chapter 6, summaries the findings, draws conclusions and makes recommendations.

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#### LITERATURE REVIEW

This chapter reviews literature on disability and screening of newborns and children for disabilities. The areas covered include the definition of disability, screening of neonates, infants and children for impairments and disabilities, practices for early detection, professionals involved, time frame for the detection, resources needed to facilitate early detection and the challenges faced by health facilities in the early detection of disabilities in infants and children.

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#### 2.0 INTRODUCTION TO DISABILITY

"Disability is a long-term physical, mental, intellectual or sensory impairments which interact with various barriers that may hinder [a person's] full and effective participation in society on an equal basis with others" (United Nation's Convention on the rights of Persons with Disability, Article 1, pp 8).

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"Disability is an umbrella term, covering impairments, activity limitations, and participation restrictions. Impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations. Disability is therefore a complex phenomenon, reflecting an interaction between features of a person's body and features of the society in which he or she lives" (WHO, 2012).

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In this study, disability is synonymous with impairment, that is, any loss or abnormality of psychological, physiological or anatomical structure or function. Persons with disabilities encounter several challenges in life as a result of limitation in activity brought on by the disability. Disability, in all forms or type, reduces the ability of an individual to function their complete talent. This can result in limitations in a person's full participation in life activities.

Most forms of disabilities among children affect their academic as well as their ability to perform socially. Disabilities sometimes occur due to some anomalies in the genes, hereditary factors and rarely due to trauma (Batul NB., 2011). Some of these disabilities

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include but not limited to visual, hearing, physical, and mental impairments.

#### 2.1 PRACTICES FOR THE EARLY DETECTION OF DISABILITIES IN

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Early identification practices refer to a comprehensive methods and processes followed in order to know the presence of a condition that may result in a developmental delay or places a child at risk for a developmental delay or poor outcome. The practices are characterized by screening or assessment practices which aim to determine condition that create or result in disabilities (American Academy of Pediatrics (AAP), 2006).

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Tools developed to screen for causal factors and developmental delays are important in improving programs designed for early intervention and the provision of services and supports to infant and children with impairments. With advancement in medical technology there exist a number of practices and good screening tools in health facilities and primary health care setups designed for different settings, age groups, and purposes to facilitate the early detection of "abnormalities" in newborn babies.

According to the National Joint Committee on Learning Disabilities (2006), the identification process (for disabilities in newborns) includes screening, examination for the presence of risk indicators and protective factors, systematic observations, and, if indicated, a comprehensive evaluation. Screening has been identified as one of the ways to identify children with disabilities. Screening helps to determine if further evaluation is necessary and to which developmental domains (Hardman et al., 1990). Irrespective of how healthier babies might appear, they still need to be screened because some conditions are hidden and therefore cannot be identify by just a quick look at the baby. Early detection of these conditions after birth can aid avert some problems deemed serious, for example, brain and organ damage which might result in death (Centre for

Disease Control and Prevention, 2011).

intervention in newborns and infants.

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There exist standard protocols, questionnaires, and screening tools that are useful in identifying developmental disabilities. An example of such tools is the Ten Question Screen (Simeonsson, 1991). It is a process of growth towards standardizing criteria and methods (cheaper and more accessible) of examination for recognition of disabilities in community settings. The ten question screen only picks up only those problems that are of great concern to families (Emily M, 2003, Afr HealthSci., 2003 Apr; 3(1):33-39).

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However, there is no common language for screening tool for detecting disabilities in newborns and infants. It appears the Ten Questions Screen is the only measure that has acceptable psychometric properties and is used in a number of countries across the world (Gell et al., 1997). The age range of 2 to 9 years is a critical developmental period. Although there seems to be protocols for this age brackets, the creation of protocols with similar qualities for children below 2 years of age would help to improve screening for early

There is therefore the need to develop and test alternative less costly but effective survey

tools. These survey tools should be suitable for use in different cultures to serve as an

alternative to the existing western instruments. Such alternatives should be adoptable to developing countries, brief and easy to interpret (Bolton and Tang, 2002).

#### 2.1.1 Infant and Child Screening for Birth Defects and Disabilities

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Screening is a reliable tool for the identification of impairments in neonates and infants and children. Kucik et al., (2008) defined neonatal screening, as a well established preventive approach that includes both clinical and biochemical screening of newborns less than one month old (Wiley online library. 2008 Nov., 82 (11): 805-811). The Oxford mini-dictionary for nurses defines Neonatal screening as "the screening test carried out on newborn babies to detect diseases that appear in the neonatal period, such as phenyl ketonuria (Guthrie test)" (Martins, 2003, pp- 442).

"Screening can imply a quick assessment procedure intended to identify children who should have an intensive diagnosis or assessment" (Meisels, 1989, p.575). Nevertheless, Developmental screening focuses at identifying children who require comprehensive evaluation for developmental delays or disabilities (Committee on Children with Disabilities, 2001). Waechter et al., (1985) outlined the crucial components of the neonatal screening process as sensitive attention to parental concerns, thoughtful inquiry about parental observations, observation of a wide variety of neonate's or child's behaviors, examination of specific developmental attainments, and screening of vision and hearing to rule out sensory impairment as a cause of the delay. Screening will likely lead to the conclusion that: the child has a disability and should be referred for early intervention services or the child does not have a disability or other significant problem or further observation is warranted to determine whether or not a disability is present (Waechter et al., 1985).

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Frankenburg (1967) suggested that a screening tool or procedure should be acceptable to the child, family and practitioner, and reliable and valid. Screening procedures should also be economical and practical for use with large numbers of persons. In addition, persons performing the screening procedure should be trained adequately and there should be resources for follow up on the results of screening, including referral for further evaluation and treatment of identified problems. There should also be child and parent teaching, anticipatory guidance and support (Waechter et al., 1985).

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According to Waechter et al., (1985), some of the screening tools or procedures used for neonatal, infant and child screening consist of the following;

- physical (head to toe) examination/assessment
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- · the use of Apgar score
- assessment of motor development and neurological status (such as suckling and swallowing reflexes, and crying)
- anthropometric measurements (height, weight and head circumference)
- monitoring the vital signs (i.e. temperature, pulse, respiration, and blood pressure for deviations)
- assessment of the special senses (i.e. assessing baby's eyes for visual impairment, and ears for hearing impairment)
- laboratory biochemical screening
- ultrasound scan
- x-rays, and
- computerised tomography.

#### 2.1.2 Maternal and Family's Obstetrical and Medical History

Screening of the newborn begins with the taking of the obstetrical history of the mother, which include information about the pregnancy, immunizations, labour, and delivery. The mother's health during pregnancy, including any use of medications, exposures to infectious diseases or environmental toxins, and the trimester in which any problems occurred are described (Waechter et al., 1985). These factors, which place the infant at risk for problems, should have been identified during the pregnancy. The length of labor and length of rupture of membranes are recorded, since these influence the infant's health. Any use of anesthesia or analgesia is also recorded indicating specific amounts and times, because this may influence the infant's alertness, activity, cardio-respiratory status and feeding behavior. The presentation of the infant and method of delivery are noted including any use of forceps (Waechter et al., 1985).

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Additionally, a family profiling which includes family, genetics, social, and environmental information that will potentially affect the health of the unborn child should be taken. The family profiling may also include information on the family's medical history, including information about inherited illnesses, congenital abnormalities, and disorders in any other infants or children. Information about the parents including their ages, general health and any recent or present illnesses is equally important and should be obtained (Waechter et al., 1985).

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Family profiling is essential because, according to Johnston et al., (2003), there may be a family history of a genetic disorder and prenatal diagnosis may have to be performed.

Also, the mother may have had complications of the pregnancy or a medical condition which could cause a malformation, alter foetal growth or affect the health of the newborn baby.

#### 2.1.3 Procedures for Early Identification in the prenatal period and in Newborns Formatted: Font color: Auto According

to the National Joint Committee on Learning Disabilities (2006), the process of identifying disabilities involves screening, examining of the existence of risk signs, systematic observation and a comprehensive evaluation. Screening has been identified as one of the ways to identify children with disabilities. The purpose of screening is to determine if additional evaluation is required and in what developmental domains (Hardman et al., 1990). Screening procedures such as, inutero screening, the Apgar assessment tool, and the Brazelton assessment scale are useful in either detecting prenatal defects or problems within the first few days after birth. These screening procedures are discussed below.

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#### 2.1.3.1 Detection of Prenatal Defects in Utero

Williams (1991) opines knowing the child from their tender age is an advantage, because it makes it easy to intercede at the beginning of a new inappropriate behavior which is likely to become self-mutilating or dangerous. Also it presents families the opportunity to get advice and support to assist them and deal with the child's difficulties.

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According to Dworetzky (1996), it may be difficult to know for sure if the embryo or fetus is healthy. However, there are many ways to discover a number of serious problems prior to birth. One method used to detect problems in the fetus is amniocentesis and it is performed when the pregnancy is between fourteen and sixteen weeks old. The process which involves examining the chromosomes of the fetus within her is done by inserting a hallow needle into the woman's abdomen and drawing out some of the amniotic fluids that surrounds the fetus. These cells are then incubated and strained so that the chromosomes can be examined easily. Another method for obtaining this chromosomal information is called Chorionic Villi Sampling. In this technique, fetal cells are removed through the birth canal with the use of a needle at about the tenth week of pregnancy (eight weeks since

conception). Such techniques are mostly often used when it is suspected that a chromosomal disorder may exist in the fetus (Dworetzky, 1996). According to Dworetzky (1996), many inherited and non-inherited disorders may affect the fetus and so should be detected early and addressed.

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Due to the risks (such as miscarriage and damage to limbs) involved in the use of these advanced techniques, such as Chorionic Villi Sampling, a new technique called Flow Cytometry with Fluorescent in Situ Hybridization or 'flow with FISH' for short, is employed instead. With this new technique, a blood sample is taken from the mother's arm and processed through a flow Cytometer, which uses a beam of laser light to sort blood cells thousands of times more rapidly than laboratory technicians with a microscope can do (Dworetzky, 1996). The fetal blood cells are given the FISH treatment, they are chemically tagged with a fluorescent dye that highlights the chromosomes when they are exposed to ultra violet light. The technique is experimental, but it appears to work well (Prince et al., 1991).

#### 2.1.3.2 The Apgar Assessment tool

The Apgar assessment scale is typically administered to all infants 1 minute after birth or delivery and again 5 minutes afterwards. The scale was devised by Apgar (1953) and measures the heart rate, reflex irritability (by facial expression), muscle tone, breathing and body skin colour. Each of the five scales may be rated as 0,1or 2; the maximum score is 2 for each of the five scale for a total of 10 points. A scale of 7 or higher is typically obtained by 90 percent of all infant. Generally, an infant with a score of 4 or less is in need of immediate medical assistance. The Apgar score is a fairly good indicator of later

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neurological or muscular difficulties. Infants found by 1 year of age to have neuromuscular or developmental problems often had low Apgar scores at birth (Dworetzky, 1996).

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#### 2.1.3.3 The Brazelton Assessment Scale

The Brazelton Neonatal Behavioral Assessment scale is also a popular assessment device with a long and valuable history (Brazelton, 1990). The scale has 28 points behavioral scale and 18 reflex scales. The assessment also includes such things as the infant's response to a human voice or face and to being touched. The scale is more difficult and time consuming to administer than the Apgar score, but it is especially valuable in assessing who may need special care and what kind of care they require.

#### 2.1.4 Assessment for Prematurity

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According to Dworetzky (1996), premature infants are those that weigh less than 5.5 pounds and are born before 35 weeks of pregnancy; prematurity accounts for 65 percent of all deaths among newborn babies. As a general rule, the lower the birth weight of a new born, the greater the risk of its death. An underweight baby is approximately 40 times more likely to die during the first month of life than is a full-term, full weight baby. Premature infants often have severe difficulty breathing, are more susceptible to infection and have feeble reflexes (Dworetzky, 1996).

The problems that premature infants face may last far beyond the first few weeks of life. Among the possible later problems that may be encountered are low intelligence, learning difficulties, hearing and vision impairment, and physical awkwardness. According to Greenberg and Crinic (1988), not all premature infants have eventual difficulties because the majority of them develop quite normally and are not discernible from their full term peers.

An infant's state can be conveniently recorded by a pressure-sensitive mattress in the infant's grip that monitors its movements. Using this technique, a doctor may be alerted to an infant with inconsistent state and can keep that baby under closer observation during

later development that would normally be necessary (Dworetzky, 1996).

Over the years, the range of techniques designed to improve care for premature infants has grown dramatically. With modern incubation and monitoring capabilities, many more premature infants are surviving than ever before. For instance, one of the most surprising ways to help a premature infant is simply to gently touch and handle the infant. As little as 45 minutes of touching per day has been shown to help infants in incubators gain weight 47 percent faster than control infants who receive stimulation other than touching and handling (Field, 1986).

#### 2.1.5 Physical Examination of the Newborn or Infant

The physical examination of the newborn baby proceeds with the assessment of all body systems using the techniques of observation and inspection, palpation, percussion, and auscultation. In the systemic review, the paediatrician, nurse or midwife considers each organ system by asking a series of questions about symptoms or making assessment related to the system. Physical examination is done initially soon after birth to rule out life threatening anomalies and to monitor vital signs. Later, a detailed examination is done (Johnston et al., 2003).

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Johnston et al., (2003) advocated that a brief examination of the baby should be carried out immediately after delivery to confirm the sex and identify any visible abnormalities such as spina bifida, cleft lip, cleft palate, or talipes equinovarus and to identify conditions requiring urgent attention such as anal atresia which may not be immediately obvious. It is important to provide a sympathetic initial explanation to the parents about any major defect noted at this time.

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All new born infants should be examined carefully within 24 hours after birth. The examiner must particularly search for anomalies like cataracts, cardiac murmurs, and dislocation of hip. According to Levene et al., (2008), clinical examination of the new born must be carried out in a regular sequence so that items are not forgotten. A useful approach is the 'head to toe' technique. Infant ought to be observed in the presence of at least one parent. To make a meaningful observation, review of the maternal history method of delivery and difficulties at birth should be consider.

The physical examination usually focuses on the following areas or regions of the body:

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General assessment: This involves measuring the temperature, pulse, respirations, blood pressure, length, weight, head circumference, activity, posture, cry and odor. Facial features: This involves a wide range of recognizable patterns of abnormalities based on facial features including chromosomal disorders such as Trisomy 21, Crouzon

Syndrome, Treacher-Collins Syndrome and Potter's Syndrome.

Colour of the body: This entails determining if the normal colour of the newborn baby is pink and if there is any deviation such as paleness, yellowish (jaundice) and bluish colouration. These abnormalities usually indicate an underlining endocrine disorder which

if not treated can lead to brain damage and its associated complications in the later years of the child.

Posture: This involves taking note of the infant's posture and range of spontaneous movements observed during the examination. For a term infant, the normal position is one with the hips abducted and partially flexed, the knees flexed and the arms abducted and flexed at the elbow. Limited movement, exaggerated or asymmetrical movements, hypotonia or stiffness could be signs of complicated labour and must be recorded. Cry: The cry of the baby should be vigorous and sustained after stimulation. A cry that is weak, high pitched or hoarse is abnormal.

*Skin appearance*: The skin is assessed for abnormal appearances such as pigmentation and naevi.

Head: The shape and size of the head as well as the size of fontanelles noted. Anterior and posterior fontanelles are palpitated and pulsations of the anterior fontanelle observed. Eyes: The eyes are examined for abnormalities. The position of the eyes in relation to the nasal bridge is determined. The conjunctiva is also assessed for haemorrhage and conjunctivitis. Any abnormal positioning of the eyes may be suggestive of a genetic disorder such as Down syndrome. Also, cataract should be carefully looked for; if a white reflex (reflex obtained by shining a light into the infant's eyes) is seen in place of normal red reflex, then a cataract should be suspected.

Mouth: The mouth is observed for cleft palate and lip. Cleft palate can be seen when the baby is crying.

*Neck*: This is examined for signs of <u>Turner's Turner's</u> syndrome or Down syndrome, which manifests in a webbed neck.

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Anus and genitalia: The genitalia are examined for undescended testes, hypospadia/ epispadia in males and imperforate vagina in females. The anus is also examined for patency; imperforate anus can sometimes occur with vaginal/bladder atresia.

The umbilicus: The umbilicus is also examined for exomphalus/umbilical hernia. The Extremities: Limbs should be moved at all the joints through the normal range of movements. The fingers and toes are examined for polydactyly. Mild positional deformities may be present, but they are of no consequence if the infant's foot can be put through a normal range of movements (Levene, et al., 2008.; Waggle, 1996 & Johnston et al., 2003).

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Although, no system so far devised is perfect, every maternity department must have a programme to screen all babies by clinical examination or ultrasound techniques. Dunn (1992) emphasized the importance of identifying the dislocated or unstable hip within the first 48 hours of life. Similarly, Levene, et al., (2008) acknowledged the importance of hip examination of the neonate by stating that the hips should be carefully examined in order to detect dislocated or dislocatable hip, which can be suspected by unequal leg lengths and asymmetry of thighs. The hip cannot usually be abducted if there is posterior dislocation (Ortolani test).

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With the arms, the range of normal movements should be passively tested. The fingers and palms should be examined for abnormalities. For example, a single palmer crease may be present in children with Down Syndrome (Levene et al., 2008).

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The upper limbs should be examined for signs of brachial plexus injury. Trauma to the brachial plexus may be due to excessive lateral flexion, rotation or traction upon the neck

and may be seen with normal delivery with impacted shoulders or during delivery of a breach presentation (Evans Jones et al., 2003).

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Brachial plexus injury can result in Erb's palsy (upper brachial plexus palsy). In this lesion, the fifth and sixth cervical nerves roots are injured and the arm will be held in adduction with the elbow extended and the forearm pronated with the wrist flexed. This is traditionally known as the 'waiter's tip' position. A dimple detected in the lower spine at the back suggests the presence of a spina bifida. Spina bifida may be occult or obvious if meningocele is present (Waggle, 1996 and Marks, 1994).

#### 2.1.6 Anthropometric Measurements

Anthropometric measurements focus on the overall physical development of the newborn and indicate the influence of various factors such as maternal health and nutrition, which can negatively impact on the intrauterine development of the baby. It assesses the growth and state of nutrition of the baby, which can be determined both by observation and by plotting the weight, length and head circumference on standard growth chart (Anupama and Dakshayani, 2013). This implies that the length, weight and head circumference of the baby should be measured. While the birth weight (with baby being naked) is measured to the nearest 10g, the head circumference is recorded as the maximum occipito-frontal circumference and the length of the baby, that is, the crown to heel measurement is recorded using the neonatal measuring board (Levene et al., 2008).

After observation the chest is auscultated. Breath sounds may have harsh quality with crepitations heard normally in first few hours after birth. Heart rate of a normal healthy newborn varies between 100 and 170 beats per minute but may be slower during sleep.

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#### 2.1.7 Neurological examination

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According to Waggle (1996) and Marks (1994), the neurological examination involves the assessment of the newborn for signs of neurological defects. This is normally done by assessing the reflexes of the neonate. The primary reflexes are present at birth, whiles secondary reflexes appear after the primary reflexes fade away. Some of the reflexes that can be assessed include;

- Suckling reflex full term infant sucks vigorously if his/her upper and lower lips
  are stimulated. Movement of the tongue and lips occur in the direction of the
  stimulus (rooting).
- Grasp reflex –this reflex is elicited by placing a finger across the palm or sole of the baby and the baby's fingers close and grasp it. This reflex normally disappears in 12 weeks.
- Moro reflex the Moro reflex is elicited by lifting the head of the infant who is in a supine position gently above the level of the bed and then releasing it suddenly on the palm of the examiner. The normal response is sudden abduction followed by adduction of both arms. The hands of the baby will open out but fingers will remain flexed. An infant with cerebral damage has an absent or exaggerated response. Also, an asymmetric response is seen in Erb's palsy, spastic hemiplegia and fracture of the humerus and clavicle. This reflex also disappears after 12 weeks.
- Head lag when baby is lifted up by his wrists to a sitting position, term infant
  momentarily keeps the head steady followed by flexion at the neck. In hypotonic
  infants, there is a head lag, that is, the head does not come forward but lags behind.

- Glabellar reflex is elicited by tapping over the root of the nose resulting in blinking. If the blinking persists after the first few taps it indicates a neurological defect in the infant.
- Crossed extension flexion, abduction and extension of the opposite leg occurs
  when the foot is stroke with the leg extended at the knee. If a stroke does not illicit
  this response, it indicates nerve damage.
- Parachute reflex is elicited by suddenly lowering the new born in ventral suspension from above for a distance normally with the arms, hands and fingers extend.

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Another useful tool or procedure for screening for neurological disabilities is the assessment of the motor activities of the neonate and its ability to respond to stimuli. According to Waggle (1996), a neonate can follow a bright, red, round object through nearly 180 degrees by movement of his eyes only if the same is held and moved in front of him. If a handkerchief is placed on his head, he actively makes arm and hand movements to push it off. He/she has preference for human faces as also for female voices.

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Purposeful hand - to - mouth movements are made if the neonate is hungry. A neonate has the ability to shut out repeatedly given noxious visual or auditory stimulus. It has the ability to give alert and orientation responses to attractive stimuli and to show coordinated eye and head or ear and head movements. A newborn can perform complex motor movements like defensive movements, cuddliness, and pull to sit movement and can be consoled with intervention and self quieting activity (Waggle, 1996). A reduced level of response (motor or sensual) could indicate a neurological or motor deformity with the potential of leading to mental retardation, mobility and sensual impairments in the future (Waggle, 1996).

#### 2.1.8 Blood Tests or Biochemical Screening

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This technique involves taking a few drops of blood from the baby's heel and sending the blood sample to a newborn screening laboratory for testing for inborn errors of metabolism and genetic disorders (Centre for Disease Control and Prevention, 2011). The laboratory test is considered along with the rest of the information about a child in making an assessment and plan of care (Waechter et al., 1985).

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According to Pandor et al., (2004) inborn errors of metabolism are a rare group of genetic disorders that can have serious clinical consequences for an affected neonate. If these conditions are not diagnosed and treated early, they can cause irreversible mental retardation (ranging from mild to severe), physical disability, neurological damage, and even fatality. Early detection and accurate diagnosis are very important for achieving a rapid and favourable outcome. For instance, a low phenylalanine diet started in the first week of life of a baby with phenylketonuria (PKU) can prevent severe mental retardation (El-Hazmi, 1997).

The genetic disorders are a frequent etiology of disability; some of the impairment features in genetic disorders are physical and obvious during clinical examination while others are concealed and only appear later. Some of these genetic disorders include skeletal abnormalities, blindness, and hearing impairment, chromosomal anomalies such as trisomy 18 or 21, Klinefelter's syndrome and Turner's syndrome (El-Hazmi, 1997). Although acquired disability due to trauma, infections, surgery, and some endocrine abnormalities or nutritional deficiencies can be recognized by taking a history of the patient and by physical and clinical examination, laboratory confirmation can help in arriving at a final diagnosis.

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Majority of the acquired disabilities can be easily diagnosed at an early stage and appropriate measures of intervention and management can be adopted accordingly. However, several other disorders such as inborn errors of metabolism do not become evident until later in life, although diagnosis may be made prior to the appearance of the disability or its complications. This diagnosis has been possible using biochemical tests and, more recently, by applying recombinant DNA technology to the identification of the molecular basis of genetic disability (El-Hazmi, 1997).

All pre-term or unwell babies should have blood taken prior to blood transfusion. This blood sample is used to screen for phenylketonuria, hypothyroidism, MCADD, cystic fibrosis, sickle cell disorders and thalassaemia major (El-Hazmi, 1997).

## 2.2 PERSONNEL RESPONSIBLE FOR THE EARLY DETECTION OF

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# DISABILIT

#### **NEWBORNS AND CHILDREN**

Developmental screening can be done by various professionals in healthcare, community, or school settings, but health professionals have a greater role to play. The role played by health professionals in developmental screening is particularly important, because of the greater emphasis placed on early identification of children with delays.

For instance, through well-child visits, health professionals have regular contacts with children 0 to 3 years-of-age, giving them the opportunity to monitor developments in children through periodic developmental screening (American Academy of Pediatrics, Council on Children with Disabilities (AAPCCD), 2007). The AAPCCD asserted that pediatric health care practitioners, in particular, play a key role in the identification, early intervention and subsequent referral of children with or at risk of developing disabilities.

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Newborn and child screening as a public health service, requires a broad social consensus support. Therefore, all stakeholders, including governments, health care providers, hospitals, clinicians, parent groups, and the public need to by consensus determine which disorders need to be added to the newborn-screening panels and the criteria to be used to decide on screening panels. This consensus development process should be premised on objective evidence-based assessments as well as sound ethical concerns.

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Newborn hearing screening, for instance, can be performed by volunteers, nurses, midwives, audiological technicians, audiologists, and other trained personnel. Initial training for those who perform newborn hearing screenings, as well as refresher trainings and periodic monitoring of staff performance, are essential to ensure quality screening. Studies have shown that on-going experience with screening is an important factor in maintaining low and accurate rates in hearing screening. (Minnesota State Statutes on Newborn Screening; (2014) Health. Chapter 144 section 144.966).

In Ghana the personnel responsible for the screening of infants and children for impairments and disabilities include the midwives, general nurses, community and public health nurses, general medical officers and paediatricians (anonymous).

According to the National Joint Committee on Learning Disabilities (2006), early identification as a process includes screening and examination for the presence of risk indicators as well as systematic observations and a comprehensive evaluation to establish whether or not a child has a disability or is at risk of developing one.

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The early years of life have been found to be critical to the overall development of children, particularly, those with disabilities as well as those at risk (National Joint Committee on Learning Disabilities, 2006). The earlier a child is identified as having a developmental delay or disability, the greater the likelihood that the child will benefit from intervention strategies designed to compensate for the child's needs. According to Gorham and Stout (1995), with the present technology, at least 50% of all disabilities may be prevented or postponed if screening is done early to detect developmental delay for intervention.

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With regard to the time frame within which disabilities in neonates are detected, there are no established time limits. However the Centre for Disease Control and Prevention (CDC) is of the view that babies born in a hospital should be screened before they leave the hospital (CDC, 2011). Parents should take babies that were not born in a hospital and those that were not screened before leaving the hospital to a hospital or clinic for screening within a few days of birth.

In some States (in the USA) all babies are screened a second time, about two weeks after birth, and National Neonatal Screening Test (NNST) should be conducted for all babies who are between 5-8 days old (CDC, 2011). In the event that screening is performed late (i.e. after 8 days) it should be written clearly on the screening card proving reasons for not performing the screening within the usual time span. On some occasions, the laboratory will request repeat samples of what and for what reason(s). For example, if needed for confirmation of cystic fibrosis status, it is important for a repeat testing to be done between days 21-28 after the last test. It has also been recommended that repeat heel prick test should be undertaken when the baby reaches the equivalent of 36 weeks gestational age (Henley and Walker, 2007).

For babies born in hospital, two clinical neonatal screenings should be conducted before discharge. The first is done within 24 hours after birth and the second is carried out after a few days. The reason for the first examination is to pick up abnormalities that may require prompt intervention and the second one aims at detecting abnormalities that may have been missed during the first screening. The second screening also helps to detect other abnormalities which may become apparent later in life as the fetal circulation of the newborn adapts to life outside the womb such as cardiac defects (Grosse et al., 2006). Grosse et al., (2006) in comparing the effectiveness of one versus two hospital neonatal screening, found that examining babies in hospital twice rather than once before discharge resulted in more congenital abnormalities being suspected. This could have resulted from more babies being examined by more experienced staff, because a second examiner might detect something that was missed at first or pick up new conditions that developed over a period (Grosse et al., 2006).

The study however revealed that the extra "diagnoses," did not lead to any appreciable increase in interventions that might improve infant's health nor did the infants from one group make extra use of emergency services. There was also no evidence that one examination was less effective than two in identifying babies who required medical attention. Although babies with suspected abnormalities underwent two instead of one hospital neonatal examination, the practice did not show any net health benefits in favour of the babies who had two examinations. A two screening policy does, however, carry additional resource implications for hospital services since more resources will be required for further screening. More than one screening also brought extra anxiety for parents whose children are wrongly suspected of having abnormalities (Grosse et al.,

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Glazener et al., (1999) suggested that screening tests should be administered at the 9<sup>th</sup>, 18<sup>th</sup>, and 30<sup>th</sup> month visits. Because the frequency of regular pediatric visits decreases after 24 months of age, a pediatrician who expects that his or her patient will have difficulty attending a 30<sup>th</sup> month visit should conduct screening during the 24<sup>th</sup> month visit.

## 2.4 RESOURCES NEEDED FOR EARLY DETECTION OF DISABILITIES IN

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#### NEWBORNS AND CHILDREN

For newborn screening facilities to provide effective screening services, they must be resourced adequately with the right resources to guarantee good results. Reliable funding sources should be available for each system component such as follow-up, diagnosis, treatment, and information systems for monitoring screening outcomes. Education of parents and care providers and adequate reimbursement for genetic counseling and case management services are also needed if newborn screening is to live up to its promise (Grosse, 2006). And this can only be done if the facilities charged to perform the screening are provided with the needed resources.

A decision as to whether to provide a public health service to the entire population should be based on the premise of evidence of benefit, risk, and cost and with full consideration of public resources available and priority targets set. Regardless of whether universal newborn screening is funded by the public or the cost element is passed on to a third-party payer or the parents, the implications for resource allocation and the opportunity cost of foregone alternatives need to be considered. Resources could potentially be provided at the expense of access to other general health care services of demonstrated and proven benefits.

Prioritization is also important when public health agencies offer other clinical services, such as immunizations and cancer screening, to people who cannot otherwise afford them (Boyle, et al., 2005).

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There have been recommendations for the use of behavioral methods for assessing for impairment in young children in developing countries because of limited fiscal and technological resources to support more sophisticated screening tests (Gell, et al., 1992). For instance, two key developmental points have been recommended in the screening for hearing impairment among infants and young children in developing countries; the first prior to the attainment of age of 2 and the second at the time of school entry, to reduce the cost involved in conducting more hearing screening for infants and children (Gell, et al., 1992). Because screening approaches based on high technology may be impractical and too costly for developing countries, screening methods that are performance based, incorporating behavioral techniques, should be applied.

The caution, however, in the implementation of such screening approaches in developing countries is that, follow-up services should be established before implementing such screening methods. The validity of screening based on behavioral methods requires sensitivity to the use of specific stimuli that are relevant and appropriate in a given country and culture. A community based screening efforts should be geared towards drawing on trained health workers to visit homes and to carry out screening using checklists for families and simple screening tests (Gell et al., 1992). Careful assessments must also be made for other screening technologies such as deoxyribonucleic acid (DNA)-based screening that can reveal disorders or variants, for which the clinical implications may be well understood (Boyle et al., 2005).

# 2.5 CHALLENGES IN THE EARLY DETECTION OF DISABILITIES IN

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INFANTS

# **CHILDREN**

Screening for the identification of impairments and disabilities among infants and children face significant challenges, especially in developing countries, due to limited resources and qualified professionals to carry out the screening (Simeonsson, 1991). Limited resources have also made it difficult to make projections about the prevalence of disability in children. For instance, Simeonsson (1991), cited lack of simple and efficient screening tools as a major factor that restricts estimation of prevalence of disability in young children in developing countries.

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Due to the limited fiscal and technological resources, behavioral methods have been recommended for assessing hearing impairment in young children in developing countries (Gell et al., 1992).

The level of state resources available (personnel, equipment, service capacity); the program's interpretations of available evidence concerning given conditions (incidence, treatability, impact); the availability of new screening methodologies; and public advocacy by families, health care professionals or state legislators have often led to divergence among states regarding which conditions should be mandated for newborn screening. In turn, this divergence has resulted in significant disparities in screening services available to infants (Simeonsson, 1991).

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The public health system and new born screening, for that matter, face many challenges.

There is limited health care service infrastructure resulting in a disconnect between primary care professionals and subspecialists, particularly in the rural areas. This problem is

worsened by the number and variety of rare conditions identified during newborn screening programs. There are limitations in the availability of specific expertise for managing many of the rare conditions. Therefore, considerable needs exist in the areas of training and education about the disorders detected through newborn screening programs throughout the health care (Simeonsson and McDevitt, 1999).

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Improvements in the newborn screening system and the expansion of the number of conditions for which screening is offered come with costs. These costs and the associated benefits seem to accrue independently of the public and private health care delivery systems thus making their integration difficult. Also, although for most screening policies, programs necessary to ensure that screening and diagnosis will occur are in place, they have limitation ensuring long-term management including the provision requisite treatment and services (Simeonsson and McDevitt, 1999).

The unavailability of standardized screening tools even in the developed countries is also a serious worry to practitioners. According to Sherman (2011), the use of standardized screening tools as recommended by the AAP is not a routine practice in most pediatric primary health care practices in certain states of the US.

The introduction of new technologies in newborn screening presents some challenges. The first is the expanding knowledge base of the etiology and therefore the treatment or potential treatment of genetic diseases. The rapid expansion of diverse technologies such as multiplex platforms that may be used in screening also presents as a challenge. The third challenge is the increased use of tiered testing strategies to enhance the positive predictive value of an initial abnormal result with its high cost element (Watson et al., 2006).

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The lack of newborn screening program uniformity for infants, the changing dynamics of emerging technology, and the complexity of genetics, require an assessment of the state of the art in newborn screening and a perspective on the future directions such programs could take (Watson et al., 2006).

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Limited funding, manpower shortages, inadequate support services, low public awareness and the uncertainty regarding the commitment from healthcare practitioners may present some challenges but these are not insurmountable. Pilot studies are necessary in each country to provide empirical data that will guide healthcare providers who wish to introduce such a programme at any level of healthcare delivery (Olusanyaa, 2003).

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Another challenge cited for neonatal screening for developmental delays is the limited ability of infant tests, whether intended for screening or definitive diagnosis of intellectual functioning, to predict future functioning and this has led to controversies concerning their use. Another challenge is inaccuracy of certain screening or diagnostic findings about disabilities. The use of the wrong kind of screening instrument could also pose a challenge to effective screening of neonates or newborns for disabilities. This is because the advantage of screening instruments is that they state their norms explicitly, serve as a reminder to the clinician to observe development, and are an efficient way to record the observations. When physicians or midwives use only clinical impressions, estimates of children's developmental status are often inaccurate (American Academy of Pediatrics, Committee on Children with Disabilities, 1993).

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Unavailability of appropriate referral centers and/or specialists is equally posing problems to the screening and early intervention in infant and childhood disabilities. Malloy et al., (2000) reported that care providers who work with young children with disabilities, other than deaf-blindness, are also struggling to get better ways to identify and provide services for children in need of early intervention. For instance, the standard practice for early detection of and intervention for hearing loss are; screening for hearing loss by age 1 month, audiologic evaluation by age 3 months, and enrollment unto appropriate intervention services by age 6 months. In the US, more than 95% of newborns are screened for hearing loss prior to hospital discharge with a reduction in the average age of identification from 24–30 months to 2–3 months. Unfortunately, many of these infants are not being enrolled in appropriate intervention services by age 6 months

(Morton & Nance, 2006; Joint Committee on Infant Hearing, 2007; Malloy, et al., 2000).

Accordingly, health professionals who do screening of newborns require continuous training to upgrade their knowledge on how to identify disabilities in newborns and also to know the appropriate intervention measures. This assertion is buttressed by Malloy et al., (2000), when they noted that early intervention in disabilities in children is the responsibility of specially trained health professionals who are mandated with the task of rendering early intervention in these disabilities.

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Olusanya et al., (2004) observed that limited funding, manpower shortages, inadequate support services, low public awareness and the uncertainty regarding the commitment from healthcare practitioners may present some challenges to neonatal screening for disabilities, but these can be dealt with. According to Padilla (2008), establishing sustainable newborn

screening programmes in developing countries poses major challenges as it competes with other health priorities like infectious disease control, immunization, and malnutrition.

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The reliance on informal community based identification of children with disabilities, which is mostly practiced in developing countries, is likely to yield substantial underestimation of disability prevalence in those countries. This is due to the fact that, stigma attached to disability may keep families from letting others know of their children's condition. Use of informal community identification could lead to missing children with less severe or hidden disabilities (Simeonsson, 1991).

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## **CHAPTER THREE**

#### RESEARCH METHODOLOGY

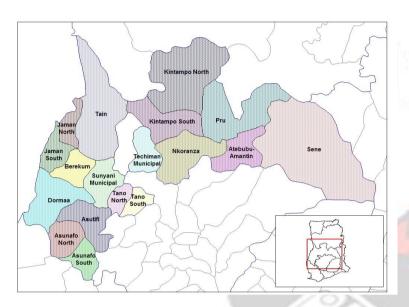
#### 3.0 INTRODUCTION

This chapter discusses the methodology for the study and covers the following: research design, study area, study population, sampling technique and sample size, the research instruments, method of data collection, pretesting as well as ethical considerations.

3.1 Study Area Formatted: Font color: Auto

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Figure 2: Map of the Brong Ahafo Region



Source: en.wikipedia.org

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The study was conducted in selected health facilities in the Brong-Ahafo Region. The region is located in mid-western Ghana and between the Ashanti Region and the Northern Region. The region is the second largest in Ghana and covers an area of 39,557 square kilometers. It shares boundaries with the Northern Region to the north, the Ashanti and Western Regions to the south, the Volta Region to the east, the Eastern

Region to the southeast and La Cote d'Ivoire to the west. The region is divided into 27 administrative districts with Sunyani as its capital.

## Population

The Brong Ahafo Region has an estimated population of 2,310, 983 accounting for approximately 9.4 percent of Ghana's population. With a land size of 39,554 km², the

population density for the region has increased from 45.9 persons/km² in 2000 to 58.4 persons/km² in 2010 (Ghana Statistical Service (GSS), 2012)

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Although the prevalence of disability in the region is lower compared to other regions, it is said to be in the increase. The most common disabilities in the region include those related to sight, hearing and speech, physical, intellectual and emotional. There are also persons with multiple disabilities (GSS, 2012).

The number of Persons with Disabilities (PWDs) in the region was 54,038 constituting 2.3 percent of the regional population. The male to female ratio was 11: 12 while urban to rural ratio was 10: 13. The proportion of PWDs in Brong Ahafo region decreases with age, thus, people less than 15 years have the least proportion of PWDs (1.19%) (GSS, 2012).

## State of Health Facilities in Brong Ahafo

The region has about 25 hospitals, 35 health centers, 106 rural clinics, and 54 maternity homes. More than half of all the health facilities in the region are owned by Government, that is, all health centers, and two-thirds of rural clinics. Three-quarters of hospitals (excluding health centres, clinics and maternity homes) and almost all maternity homes, however, are privately owned. Most of the private hospitals, notably the mission hospitals, have government-paid/seconded personnel (GHS Annual Report, 2006).

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Traditional healers and healing facilities are widely distributed throughout the region and are more accessible to especially, the rural population than all the other facilities. Over 90.0 per cent of localities in Kintampo, Atebubu, and Sene districts have traditional healers.

Berekum has the lowest proportion, with about 38.0 per cent of localities having traditional healing facilities, while the rest have more than 50.0 per cent (GHS Annual Report, 2006).

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The Sunyani municipality has the highest of health concentration of facilities with a quarter of all the hospitals in the region. The only district that has no hospital is Sene, while Jaman has the highest number of rural clinics and maternity homes. Although it is not possible to have a health facility in every community, the available facilities in the region fall short of the recommended standards with regard to the spread. Meanwhile, the Health Ministry recommends a distance of eight kilometres of a facility from a locality (GHS Annual Report, 2006).

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It is easy to access clinics than hospitals in terms of distance due to a stock of these facilities in the region. Apart from Kintampo, Atebubu and Sene, which have less than 40.0 per cent of localities within a 10-kilometre radius of a clinic, the remaining districts have more than 50.0 per cent of localities living within a 10-kilometre radius of a clinic (GHS Annual Report, 2006).

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There is a serious shortage of personnel providing direct health service, with pharmacists being the worst affected (50.0%), nurses (21.5%) and doctors (17.6%). This shortage in health service providers will lead to loss of confidence in orthodox health care (GHS Annual Report, 2006).

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Fertility and child survival: the most urbanised districts, Sunyani and Berekum, have the least fertility rates, while Sene and Asunafo which are more rural, have the highest fertility

levels. Asutifi and Atebubu are other districts with relatively higher fertility rates. So far the three Demographic and Health Surveys conducted in Ghana (1988, 1993 and 1998) have confirmed that urban woman have lower fertility indicators than rural women, and also that the higher educational level of women, the lower the fertility indicators (GHS Annual Report, 2006).

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The region has a child survival rate of 82.3 per cent, implying that less than 16 per cent of children born to women (12-49) years died. Survival rates for the districts range from 79.8 per cent in Wenchi to 85.1 per cent in Asunafo. This implies that child survival rate in the region is high (GHS Annual Report, 2006).

**Disability Situation**: It is estimated that about 54,038 (2.3%) of the region's population have disabilities with a <u>malea male</u> to female ratio for PWDs of eleven to twelve.

The regional capital Sunyani Municipal, Pru and Nkoranza South have the highest proportion of more than three percent of PWDs while Nkoranza North, Sunyani West, Atebubu Amantin and Kintampo South reported the lowest proportion of less than two percent PWDs.

Types of disabilities recorded in the census include sight, hearing and speech, physical, intellectual and emotional. Disability cases can be multiple, that is, one person can have more than one type of disability.

The proportion of PWDs in Brong Ahafo region decreases with decreasing age. Thus, people less than 15 years have the least proportion of PWDs (1.19%).

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——— (Ghana Population and Housing Census (GPHC) report, 2010).

## 3.2 STUDY POPULATION

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The target population for the study consisted of medical superintendents/directors of hospitals, nursing service administrators/matrons, midwives, public/community health nurses, medical officers (paediatricians) and laboratory technologists from selected health facilities in the region. The selected health facilities included the Sunyani municipal and regional hospitals, Goaso municipal hospital, Kintampo municipal hospital, the Saint Theresa's hospital Nkoranza, Saint Elizabeth's hospital Hwidiem, Holy Family hospital Techiman, Presbyterian hospital Dormaa- Ahenkro and the Methodist hospital Wenchi.

These health facilities were selected because they span across the various geographical locations of the region and also have similar characteristics as others in the region and therefore representative of these health facilities. Most of the respondents (61%) were working in public hospitals 26% in private hospitals, and about 13% in clinics.

3.3 RESEARCH DESIGN

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The study design was descriptive and utilized questionnaires to collect data on the capacity of health facilities to detect impairments and disabilities in newborns and

children. Fraenkel and Wallen (2000) observed that the purpose of descriptive research is to observe, describe and document aspect of phenomenon as it naturally occurs.

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According to Glass and Hopkins (1984), descriptive research can be either quantitative or qualitative. It can involve collections of quantitative information that can be tab ulated along a continuum in numerical form, such as scores on a test or the number of times a person chooses to use a —certain feature of a multimedia program, or to describe categories of information such as gender or patterns of interaction when using technology in a group situation.

Descriptive research involves gathering data that describe events and then organizing, tabulating, depicting, and describing the data collected. It often uses visual aids such as graphs and charts to aid the reader in underst anding the data distribution (Glass and Hopkins, 1984).

The researcher made use of descriptive research because it is easier and more cost effective to use. The second reason is that with descriptive research, graphs and charts are used aiding better understanding of the data distribution.

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#### 3.4 SAMPLE SIZE

In all hundred (100) participants from ten (10) selected health facilities across the Brong Ahafo region were enrolled for the study. This was made up of ten (10) par ticipants from each of the ten selected facilities. The participants comprised medical directors/superintendents; nursing administrators/matrons; medical officers, nurses and midwives working in the maternity, labour and paediatric wards; paediatricians;

biomedical scientists/laboratory technologists of the selected health facilities. For each of the selected health facilities, the medical director, the matron/nursing administrator, the head of the medical laboratory, two midwives or nurses each from the labour/maternity ward, paediatric ward, and the maternal/child and reproductive health unit were selected for the study. One paediatrician or medical officer each at the paediatric consulting room and/or at the paediatric wards from each selected health facility was also included. These health professionals were selected because they were either directly involved in the care of infants and children or carry out services that can facilitate the detection of defects or disabilities in children.

#### 3.5 SAMPLING TECHNIQUE

Districts were selected using random sampling technique, while cluster sampling technique was used to select the health facilities. In the case of selecting participants from the selected health facilities, purposive sampling technique was employed.

In selecting the districts, first, the 27 districts in the region were assigned numbers 1 to 27 and put in a container. The elements were mixed up and 9 picked out of the container at random. facilities in each of the districts written out and put in 9 different containers and labeled

Secondly, the sampled districts were noted and the names of all the health

Simple random sampling was used to select health facilities in each of the groups. This technique was chosen because the elements in the each group were homogeneous. This implies that the elements in each group had similar characteristics and provides similar services. Nine containers were assigned letters, A, B, C, D, E, F, G,

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H, and I. Container A contained elements in group 1, container B had elements in group

2, container C had elements in group 3, in that order up to the last, container I containing

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elements in group 9. The regional hospital was purposively sampled for the research due to its strategic importance as the regional referral centre.

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The elements in each of the containers were mixed up to give each health facilities equal chance of being selected. An assistant was blindfolded and asked to pick one element from each of the containers. Upon picking the health facilities from which the health personnel were sampled, a purposive sampling was used to sample the health personnel - hospital directors, nursing administrators, midwives and nurses, paediatricians, and laboratory technologists. The researcher used a purposive sampling because he wanted to target a particular group of health personnel - health personnel who attend to babies and children at the health facilities. These were people who could provide the required information due to their expertise and the services they render.

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# 3.6 RESEARCH INSTRUMENT(S)

Data for this study were obtained through two data sources: primary data sources and secondary data sources. The secondary data sources included internet sites and published works dwelling on the subject of interest. The secondary data were used to review literature on the subject of study. The primary data were obtained from respondents through the administration of structured questionnaires at the selected health facilities sites.

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#### 3.7 METHOD OF DATA COLLECTION

The data used for the study were collected personally by the researcher. Consent was sought from the respondents before administering the question. The average time taken by respondents to complete the questionnaire was 30 minutes.

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Hundred (100) questionnaires were distributed out of which eighty (80) were retrieved. The questionnaire covered the socio-demographics of respondents, early disability detection practices, personnel involved in screening of infants and children, time frame for detecting disabilities in newborns, resources needed for screening for disabilities in children, challenges faced in the screening for disabilities in babies and children and recommendations for improving the screening process in health facilities.

3.8 PRETESTING Formatted: Font color: Auto

The data collection tools were pretested in some health facilities in the Ashanti Region. It ensured that questionnaire items were clearly written and ambiguities that might have made it difficult for respondents to answer the questions eliminated. The pilot test therefore increased the reliability and validity of the data collection instrument.

3.9 DATA ANALYSIS Formatted: Font color: Auto

The analysis of the collected data was done using Statistical Package for Social Sciences (SPSS) software. The data collected were summarized into tables, graphs and charts for easier understanding.

3.10 ETHICAL CONSIDERATIONS

Clearance was obtained from the Committee on Human Research, Publications and Ethics (CHRPE) at the Kwame Nkrumah University of Science and Technology

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Permission was also obtained from the Brong Ahafo Regional Director of Health Services to undertake the study in the selected health facilities.

Prospective participants were given the questionnaires and consent forms to read through carefully and all their questions and/or concerns about the study addressed. They were then made to sign the consent form to indicate their consent to participate in the research before completing the questionnaires.

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In addition, the anonymity and confidentiality of all participants were ensured by not including or demanding the identity and/or any incriminating information on them; only group information, without identifiers, has been reported and not individual responses. The participants were also informed of their right to withdraw from the study without jeopardizing their relationship with the principal investigator or anybody.

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## RESULTS OF STUDY

## 4.0 INTRODUCTION

This chapter presents the results from the study, discussed under the following subsections: background information on respondents, early detection practices, personnel and their skill mix for early detection

of disabilities, screening schedules, challenges in early detection of disabilities, recommendations for improving on disability detection rate in infants and children.

# 4.1 ANALYSIS OF DATA

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## **4.1.1 Background Information on Respondents**

# **Table 4.1 Gender of respondents**

Sex	Frequency	Percent
Male	30	37.5
Female	47	58.8
No response	3	3.8
Total	80	100.0

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#### **CHAPTER ONE**

#### INTRODUCTION

#### 1.0 BACKGROUND TO THE STUDY

Although the health delivery system in some developing countries has gradually improved over the years, a lot of questions still arise concerning the capacity of the various health facilities such as hospitals, clinics, and maternity homes to facilitate the early detection of "abnormal" conditions in children to avert permanent disabilities in future (Cole & Flexer, 2007). Health facilities can effectively perform this function if the referral system is effective and they are well equipped with the appropriate resources such as skilled health personnel who can perform screening in newborns and children, screening equipment/tools, and funds (Cole & Flexer, 2007).

Another important consideration for screening for early detection of potential disabilities in children is the time frame. It is vital that "abnormalities" are detected early enough so that measures can be taken to prevent permanent disabilities. The early years of infants are very critical especially to developing language and communication since it is the time when the brain is at its highest capacity of development and undergoes some structural changes in response to external stimulation (Cole & Flexer, 2007).

The American Academy of Paediatrics (AAP) (2002), states in its policy document that, early identification of developmental disorders is critical to the well-being of children and their families. It is the function of the primary health care and the responsibility of all pediatric health care professionals. Hence, screening newborns does not only leads to children benefiting from treatment but also give access to support and services that can lead to various profits to the child and the families.

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Studies have revealed that the rate of current developmental disorders detection rates are lesser than their real prevalence in developing countries, this implies that the numerous setback to identifying developmental disorders among children are not yet overcome especially in health facilities in non-industrialized countries (AAP, 2002).

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The availability of appropriate assessment tools for screening newborns could increase the effectiveness of health facilities to detect disabilities in newborns. For instance, at the birth of every child at hospitals and other health facilities, an Apgar assessment is administered to the child one minute after birth or delivery and again after five minutes, to ascertain the likelihood of the neonate developing disabilities. It involves examining the heart rate, reflex irritability (by facial expression), muscle tone, breathing and skin colour. The Brazelton's (1990) Neonatal Behavioral Assessment Scale is also a popular assessment tool that is valuable in the assessment of newborns for need of special care.

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Pediatricians and midwives and other health professionals employ physical examination to conduct assessment on the newborn child to see if the child has a defect or not. They do this by listening to the cry of the new born child, observing the color of the eye, its physical appearance and the color of the skin. Through these assessments they are able to identify whether or not a child has a disability or is likely to develop a disability (Boyle CA et al., 2005).

It is also worth noting that screening of infants and children for disabilities encounter myriad of challenges which can make its full implementation difficult if not impossible. Challenges, such as, lack of highly accurate screening tests, high cost and unaffordable screening tests, inequities in access to expanded screening, absence of a voluntary system

of screening with informed consent, and inadequate systems of follow-up and support for families, are but some of the challenges (Boyle CA et al., 2005).

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These notwithstanding, the benefits of the concept of primary health care screening for neonatal disabilities will outweigh the negatives if well embraced. So if infant and child screening is worth doing, it has to be done well (Boyle CA et al., 2005).

#### 1.1 PROBLEM STATEMENT

It is estimated that about 15% of the world's population live with some form of disability, of which 2-4% experience significant functional difficulties (World Health Organisation (WHO), 2012). Approximately 80 percent of Persons with disability live in low-income countries (Ayiku, 2012). According to the same report, at least 81,200,000 people affected by some form of disability live in Africa (10%). The report further states that 75% - 80% of persons with disabilities in the Region of Africa are found within the rural areas, which have no or limited rehabilitation and prevention services.

Globally, there is a projected increase in the number of children with disabilities, particularly in developing countries, due to factors such as malnutrition, diseases, child labor, armed conflict and violence (Boyle and Cordero, 2005). For instance, about 3% of children born in the United States suffer a major birth defect with birth defects accounting for about 20% of all infant deaths. About 17% of children in the United States are said to have developmental disabilities, with about 2% having a disabilities severe enough to require life-long care and special services (Boyle and Cordero, 2005).

Disability is becoming a major problem in Ghana. Although statistics on disability in Ghana especially on children, is difficult to obtain, the 2010 population and housing

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census estimates that 3 percent (737,743) of Ghanaians were living with one form of disability or the other with visual impairment being the highest. The prevalence rate of disability in Ghana generally increases with age. The disability prevalence rate increases from 1.4 percent at age group 0–14 years to 3.1 percent for those aged 15–64 years then to 14 percent at age 65+ years (Ghana Statistical Services (GSS), 2012). It is estimated that, there were 54,038 persons with disabilities in the Brong Ahafo region. This constitutes 2.3 percent of the population for the region (GSS, 2012).

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In a study conducted by the United Nations International Children's Emergency Fund (UNICEF) in 18 low and middle income countries including Ghana, 23% of children aged 2–9 years screened positive for disability in the 18 participating countries. In Ghana it was found that of a total 5,391 children screened, 21 % were positive for disability (Gottlieb et al., 2006).

However, despite the rising interest in child disability, little is known about the frequency and situation of children with disabilities in countries with low and middle incomes (Grantham-McGregor et al., 2007). Although there is no accurate data on the prevalence rate for children with disabilities in Ghana, conditions in Ghana would likely cause an increase in the prevalence rate.

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The question that arises is whether the health facilities in Ghana are prepared and capable of conducting screening of infants and children for the early detection of impairments for prompt intervention (anonymous). Without the needed facilities and equipment for early detection and prevention, there is likely to be an increase in the prevalence of disability

among children in Ghana. In order to curtail this, early detection measures would have to be instituted and promoted in health facilities in Ghana.

This study therefore aims at assessing the capacity of health facilities to facilitate the early detection of disabilities in neonates and children for early intervention in order to reduce the impact on the developing competencies of children.

#### 1.2 RESEARCH QUESTIONS

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- 1. What are the practices applied in health facilities for the early detection of disabilities in neonates and children?
- 2. What are the resources (skilled personnel, technologies/equipment, and funding) at the disposal of institutions in the early detection of disabilities in neonates and children?
- 3. What are the challenges faced by health facilities and the personnel in the early detection of disabilities in children?

# 1.3 GENERAL OBJECTIVE

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The main objective of the study is to assess the capacity of health facilities for the early detection of disabilities in children.

# 1.4 SPECIFIC OBJECTIVES

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- 1. To identify the existing practices with respect to the detection of disabilities in neonates and children.
- To identify and assess the resources (skilled personnel, technologies/ equipment, and funding) at the disposal of institutions for early detection of disabilities in neonates and children

To examine the challenges faced by the various health personnel and health facilities in screening for early detection of disabilities in neonates and children.

## 1.5 SIGNIFICANCE OF THE STUDY

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The study will provide empirical data on existing practices or procedures in health facilities across the Brong Ahafo Region of Ghana regarding the early detection of disabilities in children for early intervention. The study also seeks to identify the existing resources (technological, skilled personnel, and funds) and challenges that impact negatively on the ability of health facilities to undertake early detection of disabilities in children. The study will therefore provide information on the capacities of these health facilities and the challenges they face in order for the appropriate authorities to take measures to improve upon their capacity for early detection of disabilities in children. Based on the findings, recommendations will be made to appropriate authorities to encourage a compulsory nationwide programme for screening of all newborns and children at health facilities for early detection of impairments and disabilities for early intervention.

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Finally, the study report will be used as material for reference mostly to students and people who are interested in issues concerning disability (especially early detection and intervention in childhood disabilities) for further research in this area.

## 1.6 ASSUMPTION OF THE STUDY

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The assumption of the study is that health facilities/hospitals within the Brong Ahafo Region of Ghana do not have the capacity to facilitate the early detection of all forms of disabilities in children for prompt intervention.

## 1.7 LIMITATION OF THE STUDY Formatted: Font color: Auto

The study was limited to medical directors, nursing administrators, medical officers, nurses and midwives in the maternity, labour and paediatric wards, paediatricians and biomedical scientists/laboratory technologists of selected hospitals in the Brong Ahafo Region. The study did not involve other health personnel who are not in management positions or do not directly care for newborns or children in the selected health facilities.

# 1.8 CONCEPTUAL FRAMEWORK Early Disability Detection practices Capacity of Facility to detect disability in

children

Figure 1: Conceptual Framework

(Source: Author's Construct)

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## **Explanation of the Conceptual Framework**

challenges in Disability

Detection

The capacity of a health facility to promote the early detection of disabilities in children-

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a direct correlation with the availability of the requisite skilled health personnel who are well trained. Appropriate early detection practices such as screening, thorough

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Requisite skilled health

personel &

Available Resources physical examination, and the use of the Apgar score will facilitate the early detection of disabilities in infants and children.

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For these professionals to execute the task of early identification of disabilities in children within a reasonable time frame, they need to have the requisite screening tools and equipment. Also, for the sustenance of an effective screening programme, the health facility needs regular source of funds. The time frame within which disabilities can be detected by these health personnel is also directly linked to the challenges they face in the course of undertaking the screening of newborns for disabilities.

#### 1.9 STRUCTURE OF THE STUDY

The study have six chapters. The first chapter, presents the study and also outlines the statement of the problem, and states the rationale for the study. In this same chapter, the study's questions and objectives and the delimitations are also spelt out.

The second chapter presents literature related to the capacity of health facilities to ensure early detection of disabilities in children under the following areas: practices/screening procedures for the detection of disabilities in children, personnel responsible for detection of disabilities in children, resources/technologies for early detection of disabilities in children, and challenges faced by health facilities and health personnel in detecting disabilities in children.

The study methodology is captured in chapter three, it entails the study population, research design, the sampling technique employed and sample size, the research instruments as well as the method used in collecting the data, data analysis, pretesting of data collection tools and the ethical considerations.

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Chapter four presents the study findings, while Chapter five presents the discussions of the findings. The final chapter, chapter 6, summaries the findings, draws conclusions and makes recommendations.

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LITERATURE REVIEW

This chapter reviews literature on disability and screening of newborns and children for disabilities. The areas covered include the definition of disability, screening of neonates, infants and children for impairments and disabilities, practices for early detection, professionals involved, time frame for the detection, resources needed to facilitate early detection and the challenges faced by health facilities in the early detection of disabilities in infants and children.

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2.0 INTRODUCTION TO DISABILITY

"Disability is a long-term physical, mental, intellectual or sensory impairments which interact with various barriers that may hinder [a person's] full and effective participation in society on an equal basis with others" (United Nation's Convention on the rights of Persons with Disability, Article 1, pp 8).

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"Disability is an umbrella term, covering impairments, activity limitations, and participation restrictions. Impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations. Disability is therefore a complex phenomenon, reflecting an interaction between features of a person's body and features of the society in which he or she lives" (WHO, 2012).

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In this study, disability is synonymous with impairment, that is, any loss or abnormality of psychological, physiological or anatomical structure or function. Persons with disabilities encounter several challenges in life as a result of limitation in activity brought on by the disability. Disability, in all forms or type, reduces the ability of an individual to function their complete talent. This can result in limitations in a person's full participation in life activities.

Most forms of disabilities among children affect their academic as well as their ability to perform socially. Disabilities sometimes occur due to some anomalies in the genes, hereditary factors and rarely due to trauma (Batul NB., 2011). Some of these disabilities

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### 2.1 PRACTICES FOR THE EARLY DETECTION OF DISABILITIES IN

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#### NEONATES AND CHILDREN

Early identification practices refer to a comprehensive methods and processes followed in order to know the presence of a condition that may result in a developmental delay or places a child at risk for a developmental delay or poor outcome. The practices are characterized by screening or assessment practices which aim to determine condition that create or result in disabilities (American Academy of Pediatrics (AAP), 2006).

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Tools developed to screen for causal factors and developmental delays are important in improving programs designed for early intervention and the provision of services and supports to infant and children with impairments. With advancement in medical technology there exist a number of practices and good screening tools in health facilities and primary health care setups designed for different settings, age groups, and purposes to facilitate the early detection of "abnormalities" in newborn babies.

According to the National Joint Committee on Learning Disabilities (2006), the identification process (for disabilities in newborns) includes screening, examination for the presence of risk indicators and protective factors, systematic observations, and, if indicated, a comprehensive evaluation. Screening has been identified as one of the ways to identify children with disabilities. Screening helps to determine if further evaluation is necessary and to which developmental domains (Hardman et al., 1990). Irrespective of how healthier babies might appear, they still need to be screened because some conditions are hidden and therefore cannot be identify by just a quick look at the baby. Early detection of these conditions after birth can aid avert some problems deemed serious, for example, brain and organ damage which might result in death (Centre for

Disease Control and Prevention, 2011).

intervention in newborns and infants.

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There exist standard protocols, questionnaires, and screening tools that are useful in identifying developmental disabilities. An example of such tools is the Ten Question Screen (Simeonsson, 1991). It is a process of growth towards standardizing criteria and methods (cheaper and more accessible) of examination for recognition of disabilities in community settings. The ten question screen only picks up only those problems that are of great concern to families (Emily M, 2003, Afr HealthSci., 2003 Apr; 3(1):33-39).

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However, there is no common language for screening tool for detecting disabilities in newborns and infants. It appears the Ten Questions Screen is the only measure that has acceptable psychometric properties and is used in a number of countries across the world (Gell et al., 1997). The age range of 2 to 9 years is a critical developmental period. Although there seems to be protocols for this age brackets, the creation of protocols with similar qualities for children below 2 years of age would help to improve screening for early

There is therefore the need to develop and test alternative less costly but effective survey tools. These survey tools should be suitable for use in different cultures to serve as an

alternative to the existing western instruments. Such alternatives should be adoptable to developing countries, brief and easy to interpret (Bolton and Tang, 2002).

### 2.1.1 Infant and Child Screening for Birth Defects and Disabilities

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Screening is a reliable tool for the identification of impairments in neonates and infants and children. Kucik et al., (2008) defined neonatal screening, as a well established preventive approach that includes both clinical and biochemical screening of newborns less than one month old (Wiley online library. 2008 Nov., 82 (11): 805-811). The Oxford mini-dictionary for nurses defines Neonatal screening as "the screening test carried out on newborn babies to detect diseases that appear in the neonatal period, such as phenyl ketonuria (Guthrie test)" (Martins, 2003, pp- 442).

"Screening can imply a quick assessment procedure intended to identify children who should have an intensive diagnosis or assessment" (Meisels, 1989, p.575). Nevertheless, Developmental screening focuses at identifying children who require comprehensive evaluation for developmental delays or disabilities (Committee on Children with Disabilities, 2001). Waechter et al., (1985) outlined the crucial components of the neonatal screening process as sensitive attention to parental concerns, thoughtful inquiry about parental observations, observation of a wide variety of neonate's or child's behaviors, examination of specific developmental attainments, and screening of vision and hearing to rule out sensory impairment as a cause of the delay. Screening will likely lead to the conclusion that; the child has a disability and should be referred for early intervention services or the child does not have a disability or other significant problem or further observation is warranted to determine whether or not a disability is present (Waechter et al., 1985).

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Frankenburg (1967) suggested that a screening tool or procedure should be acceptable to the child, family and practitioner, and reliable and valid. Screening procedures should also be economical and practical for use with large numbers of persons. In addition, persons performing the screening procedure should be trained adequately and there should be resources for follow up on the results of screening, including referral for further evaluation and treatment of identified problems. There should also be child and parent teaching, anticipatory guidance and support (Waechter et al., 1985).

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According to Waechter et al., (1985), some of the screening tools or procedures used for neonatal, infant and child screening consist of the following;

- physical (head to toe) examination/assessment
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- the use of Apgar score
- assessment of motor development and neurological status (such as suckling and swallowing reflexes, and crying)
- anthropometric measurements (height, weight and head circumference)
- monitoring the vital signs (i.e. temperature, pulse, respiration, and blood pressure for deviations)
- assessment of the special senses (i.e. assessing baby's eyes for visual impairment,
   and ears for hearing impairment)
- laboratory biochemical screening
- ultrasound scan
- · x-rays, and
- computerised tomography.

## 2.1.2 Maternal and Family's Obstetrical and Medical History

Screening of the newborn begins with the taking of the obstetrical history of the mother, which include information about the pregnancy, immunizations, labour, and delivery.

The mother's health during pregnancy, including any use of medications, exposures to infectious diseases or environmental toxins, and the trimester in which any problems occurred are described (Waechter et al., 1985). These factors, which place the infant at risk for problems, should have been identified during the pregnancy. The length of labor and length of rupture of membranes are recorded, since these influence the infant's health. Any use of anesthesia or analgesia is also recorded indicating specific amounts and times, because this may influence the infant's alertness, activity, cardio-respiratory status and feeding behavior. The presentation of the infant and method of delivery are noted including any use of forceps (Waechter et al., 1985).

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Additionally, a family profiling which includes family, genetics, social, and environmental information that will potentially affect the health of the unborn child should be taken. The family profiling may also include information on the family's medical history, including information about inherited illnesses, congenital abnormalities, and disorders in any other infants or children. Information about the parents including their ages, general health and any recent or present illnesses is equally important and should be obtained (Waechter et al., 1985).

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Family profiling is essential because, according to Johnston et al., (2003), there may be a family history of a genetic disorder and prenatal diagnosis may have to be performed.

Also, the mother may have had complications of the pregnancy or a medical condition which could cause a malformation, alter foetal growth or affect the health of the newborn baby.

2.1.3 Procedures for Early Identification in the prenatal period and in Newborns Formatted: Font color: Auto According

to the National Joint Committee on Learning Disabilities (2006), the process of identifying disabilities involves screening, examining of the existence of risk signs, systematic observation and a comprehensive evaluation. Screening has been identified as one of the ways to identify children with disabilities. The purpose of screening is to determine if additional evaluation is required and in what developmental domains (Hardman et al., 1990). Screening procedures such as, inutero screening, the Apgar assessment tool, and the Brazelton assessment scale are useful in either detecting prenatal defects or problems within the first few days after birth. These screening procedures are discussed below.

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#### 2.1.3.1 Detection of Prenatal Defects in Utero

Williams (1991) opines knowing the child from their tender age is an advantage, because it makes it easy to intercede at the beginning of a new inappropriate behavior which is likely to become self-mutilating or dangerous. Also it presents families the opportunity to get advice and support to assist them and deal with the child's difficulties.

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According to Dworetzky (1996), it may be difficult to know for sure if the embryo or fetus is healthy. However, there are many ways to discover a number of serious problems prior to birth. One method used to detect problems in the fetus is amniocentesis and it is performed when the pregnancy is between fourteen and sixteen weeks old. The process which involves examining the chromosomes of the fetus within her is done by inserting a hallow needle into the woman's abdomen and drawing out some of the amniotic fluids that surrounds the fetus. These cells are then incubated and strained so that the chromosomes can be examined easily. Another method for obtaining this chromosomal information is called Chorionic Villi Sampling. In this technique, fetal cells are removed through the birth canal with the use of a needle at about the tenth week of pregnancy (eight weeks since

conception). Such techniques are mostly often used when it is suspected that a chromosomal disorder may exist in the fetus (Dworetzky, 1996). According to Dworetzky (1996), many inherited and non-inherited disorders may affect the fetus and so should be detected early and addressed.

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Due to the risks (such as miscarriage and damage to limbs) involved in the use of these advanced techniques, such as Chorionic Villi Sampling, a new technique called Flow Cytometry with Fluorescent in Situ Hybridization or 'flow with FISH' for short, is employed instead. With this new technique, a blood sample is taken from the mother's arm and processed through a flow Cytometer, which uses a beam of laser light to sort blood cells thousands of times more rapidly than laboratory technicians with a microscope can do (Dworetzky, 1996). The fetal blood cells are given the FISH treatment, they are chemically tagged with a fluorescent dye that highlights the chromosomes when they are exposed to ultra violet light. The technique is experimental, but it appears to work well (Prince et al., 1991).

## 2.1.3.2 The Apgar Assessment tool

The Apgar assessment scale is typically administered to all infants 1 minute after birth or delivery and again 5 minutes afterwards. The scale was devised by Apgar (1953) and measures the heart rate, reflex irritability (by facial expression), muscle tone, breathing and body skin colour. Each of the five scales may be rated as 0,1or 2; the maximum score is 2 for each of the five scale for a total of 10 points. A scale of 7 or higher is typically obtained by 90 percent of all infant. Generally, an infant with a score of 4 or less is in need of immediate medical assistance. The Apgar score is a fairly good indicator of later

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neurological or muscular difficulties. Infants found by 1 year of age to have neuromuscular or developmental problems often had low Apgar scores at birth (Dworetzky, 1996).

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#### 2.1.3.3 The Brazelton Assessment Scale

The Brazelton Neonatal Behavioral Assessment scale is also a popular assessment device with a long and valuable history (Brazelton, 1990). The scale has 28 points behavioral scale and 18 reflex scales. The assessment also includes such things as the infant's response to a human voice or face and to being touched. The scale is more difficult and time consuming to administer than the Apgar score, but it is especially valuable in assessing who may need special care and what kind of care they require.

#### 2.1.4 Assessment for Prematurity

According to Dworetzky (1996), premature infants are those that weigh less than 5.5 pounds and are born before 35 weeks of pregnancy; prematurity accounts for 65 percent of all deaths among newborn babies. As a general rule, the lower the birth weight of a new born, the greater the risk of its death. An underweight baby is approximately 40 times more likely to die during the first month of life than is a full-term, full weight baby. Premature infants often have severe difficulty breathing, are more susceptible to infection and have feeble reflexes (Dworetzky, 1996).

The problems that premature infants face may last far beyond the first few weeks of life. Among the possible later problems that may be encountered are low intelligence, learning difficulties, hearing and vision impairment, and physical awkwardness. According to Greenberg and Crinic (1988), not all premature infants have eventual difficulties because the majority of them develop quite normally and are not discernible from their full term peers.

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An infant's state can be conveniently recorded by a pressure-sensitive mattress in the infant's grip that monitors its movements. Using this technique, a doctor may be alerted to an infant with inconsistent state and can keep that baby under closer observation during later development that would normally be necessary (Dworetzky, 1996).

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Over the years, the range of techniques designed to improve care for premature infants has grown dramatically. With modern incubation and monitoring capabilities, many more premature infants are surviving than ever before. For instance, one of the most surprising ways to help a premature infant is simply to gently touch and handle the infant. As little as 45 minutes of touching per day has been shown to help infants in incubators gain weight 47 percent faster than control infants who receive stimulation other than touching and handling (Field, 1986).

### 2.1.5 Physical Examination of the Newborn or Infant

The physical examination of the newborn baby proceeds with the assessment of all body systems using the techniques of observation and inspection, palpation, percussion, and auscultation. In the systemic review, the paediatrician, nurse or midwife considers each organ system by asking a series of questions about symptoms or making assessment related to the system. Physical examination is done initially soon after birth to rule out life threatening anomalies and to monitor vital signs. Later, a detailed examination is done (Johnston et al., 2003).

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Johnston et al., (2003) advocated that a brief examination of the baby should be carried out immediately after delivery to confirm the sex and identify any visible abnormalities such

as spina bifida, cleft lip, cleft palate, or talipes equinovarus and to identify conditions requiring urgent attention such as anal atresia which may not be immediately obvious. It is important to provide a sympathetic initial explanation to the parents about any major defect noted at this time.

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All new born infants should be examined carefully within 24 hours after birth. The examiner must particularly search for anomalies like cataracts, cardiac murmurs, and dislocation of hip. According to Levene et al., (2008), clinical examination of the new born must be carried out in a regular sequence so that items are not forgotten. A useful approach is the 'head to toe' technique. Infant ought to be observed in the presence of at least one parent. To make a meaningful observation, review of the maternal history method of delivery and difficulties at birth should be consider.

The physical examination usually focuses on the following areas or regions of the body:

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General assessment: This involves measuring the temperature, pulse, respirations, blood pressure, length, weight, head circumference, activity, posture, cry and odor. Facial features: This involves a wide range of recognizable patterns of abnormalities based on facial features including chromosomal disorders such as Trisomy 21, Crouzon

Syndrome, Treacher-Collins Syndrome and Potter's Syndrome. *Colour of the body*: This entails determining if the normal colour of the newborn baby is pink and if there is any deviation such as paleness, yellowish (jaundice) and bluish colouration. These abnormalities usually indicate an underlining endocrine disorder which if not treated can lead to brain damage and its associated complications in the later years of the child.

**Posture**: This involves taking note of the infant's posture and range of spontaneous movements observed during the examination. For a term infant, the normal position is one with the hips abducted and partially flexed, the knees flexed and the arms abducted and flexed at the elbow. Limited movement, exaggerated or asymmetrical movements, hypotonia or stiffness could be signs of complicated labour and must be recorded. **Cry**: The cry of the baby should be vigorous and sustained after stimulation. A cry that is weak, high pitched or hoarse is abnormal.

Skin appearance: The skin is assessed for abnormal appearances such as pigmentation and

Head: The shape and size of the head as well as the size of fontanelles noted. Anterior and posterior fontanelles are palpitated and pulsations of the anterior fontanelle observed. Eyes: The eyes are examined for abnormalities. The position of the eyes in relation to the nasal bridge is determined. The conjunctiva is also assessed for haemorrhage and conjunctivitis. Any abnormal positioning of the eyes may be suggestive of a genetic disorder such as Down syndrome. Also, cataract should be carefully looked for; if a white reflex (reflex obtained by shining a light into the infant's eyes) is seen in place of normal red reflex, then a cataract should be suspected.

**Mouth**: The mouth is observed for cleft palate and lip. Cleft palate can be seen when the baby is crying.

*Neck*: This is examined for signs of <u>Turner's Turner's</u> syndrome or Down syndrome, which manifests in a webbed neck.

Anus and genitalia: The genitalia are examined for undescended testes, hypospadia/ epispadia in males and imperforate vagina in females. The anus is also examined for patency; imperforate anus can sometimes occur with vaginal/bladder atresia.

The umbilicus: The umbilicus is also examined for exomphalus/umbilical hernia. The Extremities: Limbs should be moved at all the joints through the normal range of movements. The fingers and toes are examined for polydactyly. Mild positional deformities may be present, but they are of no consequence if the infant's foot can be put through a normal range of movements (Levene, et al., 2008.; Waggle, 1996 & Johnston et al., 2003).

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Although, no system so far devised is perfect, every maternity department must have a programme to screen all babies by clinical examination or ultrasound techniques. Dunn (1992) emphasized the importance of identifying the dislocated or unstable hip within the first 48 hours of life. Similarly, Levene, et al., (2008) acknowledged the importance of hip examination of the neonate by stating that the hips should be carefully examined in order to detect dislocated or dislocatable hip, which can be suspected by unequal leg lengths and asymmetry of thighs. The hip cannot usually be abducted if there is posterior dislocation (Ortolani test).

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With the arms, the range of normal movements should be passively tested. The fingers and palms should be examined for abnormalities. For example, a single palmer crease may be present in children with Down Syndrome (Levene et al., 2008).

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The upper limbs should be examined for signs of brachial plexus injury. Trauma to the brachial plexus may be due to excessive lateral flexion, rotation or traction upon the neck and may be seen with normal delivery with impacted shoulders or during delivery of a breach presentation (Evans Jones et al., 2003).

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Brachial plexus injury can result in Erb's palsy (upper brachial plexus palsy). In this lesion, the fifth and sixth cervical nerves roots are injured and the arm will be held in adduction with the elbow extended and the forearm pronated with the wrist flexed. This is traditionally known as the 'waiter's tip' position. A dimple detected in the lower spine at the back suggests the presence of a spina bifida. Spina bifida may be occult or obvious if meningocele is present (Waggle, 1996 and Marks, 1994).

#### 2.1.6 Anthropometric Measurements

Anthropometric measurements focus on the overall physical development of the newborn and indicate the influence of various factors such as maternal health and nutrition, which can negatively impact on the intrauterine development of the baby. It assesses the growth and state of nutrition of the baby, which can be determined both by observation and by plotting the weight, length and head circumference on standard growth chart (Anupama and Dakshayani, 2013). This implies that the length, weight and head circumference of the baby should be measured. While the birth weight (with baby being naked) is measured to the nearest 10g, the head circumference is recorded as the maximum occipito-frontal circumference and the length of the baby, that is, the crown to heel measurement is recorded using the neonatal measuring board (Levene et al., 2008).

After observation the chest is auscultated. Breath sounds may have harsh quality with crepitations heard normally in first few hours after birth. Heart rate of a normal healthy newborn varies between 100 and 170 beats per minute but may be slower during sleep.

#### 2.1.7 Neurological examination

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According to Waggle (1996) and Marks (1994), the neurological examination involves the assessment of the newborn for signs of neurological defects. This is normally done by assessing the reflexes of the neonate. The primary reflexes are present at birth, whiles secondary reflexes appear after the primary reflexes fade away. Some of the reflexes that can be assessed include;

- Suckling reflex full term infant sucks vigorously if his/her upper and lower lips
  are stimulated. Movement of the tongue and lips occur in the direction of the
  stimulus (rooting).
- Grasp reflex this reflex is elicited by placing a finger across the palm or sole of
  the baby and the baby's fingers close and grasp it. This reflex normally disappears
  in 12 weeks.
- Moro reflex the Moro reflex is elicited by lifting the head of the infant who is in a supine position gently above the level of the bed and then releasing it suddenly on the palm of the examiner. The normal response is sudden abduction followed by adduction of both arms. The hands of the baby will open out but fingers will remain flexed. An infant with cerebral damage has an absent or exaggerated response. Also, an asymmetric response is seen in Erb's palsy, spastic hemiplegia and fracture of the humerus and clavicle. This reflex also disappears after 12 weeks.
- Head lag when baby is lifted up by his wrists to a sitting position, term infant
  momentarily keeps the head steady followed by flexion at the neck. In hypotonic
  infants, there is a head lag, that is, the head does not come forward but lags behind.
- Glabellar reflex is elicited by tapping over the root of the nose resulting in blinking. If the blinking persists after the first few taps it indicates a neurological defect in the infant.

- Crossed extension flexion, abduction and extension of the opposite leg occurs
  when the foot is stroke with the leg extended at the knee. If a stroke does not illicit
  this response, it indicates nerve damage.
- Parachute reflex is elicited by suddenly lowering the new born in ventral suspension from above for a distance normally with the arms, hands and fingers extend.

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Another useful tool or procedure for screening for neurological disabilities is the assessment of the motor activities of the neonate and its ability to respond to stimuli. According to Waggle (1996), a neonate can follow a bright, red, round object through nearly 180 degrees by movement of his eyes only if the same is held and moved in front of him. If a handkerchief is placed on his head, he actively makes arm and hand movements to push it off. He/she has preference for human faces as also for female voices.

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Purposeful hand - to - mouth movements are made if the neonate is hungry. A neonate has the ability to shut out repeatedly given noxious visual or auditory stimulus. It has the ability to give alert and orientation responses to attractive stimuli and to show coordinated eye and head or ear and head movements. A newborn can perform complex motor movements like defensive movements, cuddliness, and pull to sit movement and can be consoled with intervention and self quieting activity (Waggle, 1996). A reduced level of response (motor or sensual) could indicate a neurological or motor deformity with the potential of leading to mental retardation, mobility and sensual impairments in the future (Waggle, 1996).

### 2.1.8 Blood Tests or Biochemical Screening

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This technique involves taking a few drops of blood from the baby's heel and sending the blood sample to a newborn screening laboratory for testing for inborn errors of metabolism and genetic disorders (Centre for Disease Control and Prevention, 2011). The laboratory test is considered along with the rest of the information about a child in making an assessment and plan of care (Waechter et al., 1985).

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According to Pandor et al., (2004) inborn errors of metabolism are a rare group of genetic disorders that can have serious clinical consequences for an affected neonate. If these conditions are not diagnosed and treated early, they can cause irreversible mental retardation (ranging from mild to severe), physical disability, neurological damage, and even fatality. Early detection and accurate diagnosis are very important for achieving a rapid and favourable outcome. For instance, a low phenylalanine diet started in the first week of life of a baby with phenylketonuria (PKU) can prevent severe mental retardation (El-Hazmi, 1997).

The genetic disorders are a frequent etiology of disability; some of the impairment features in genetic disorders are physical and obvious during clinical examination while others are concealed and only appear later. Some of these genetic disorders include skeletal abnormalities, blindness, and hearing impairment, chromosomal anomalies such as trisomy 18 or 21, Klinefelter's syndrome and Turner's syndrome (El-Hazmi, 1997). Although acquired disability due to trauma, infections, surgery, and some endocrine abnormalities or nutritional deficiencies can be recognized by taking a history of the patient and by physical and clinical examination, laboratory confirmation can help in arriving at a final diagnosis.

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Majority of the acquired disabilities can be easily diagnosed at an early stage and appropriate measures of intervention and management can be adopted accordingly. However, several other disorders such as inborn errors of metabolism do not become evident until later in life, although diagnosis may be made prior to the appearance of the disability or its complications. This diagnosis has been possible using biochemical tests and, more recently, by applying recombinant DNA technology to the identification of the molecular basis of genetic disability (El-Hazmi, 1997).

All pre-term or unwell babies should have blood taken prior to blood transfusion. This blood sample is used to screen for phenylketonuria, hypothyroidism, MCADD, cystic fibrosis, sickle cell disorders and thalassaemia major (El-Hazmi, 1997).

### 2.2 PERSONNEL RESPONSIBLE FOR THE EARLY DETECTION OF

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# DISABILITIES IN NEWBORNS AND CHILDREN

Developmental screening can be done by various professionals in healthcare, community, or school settings, but health professionals have a greater role to play. The role played by health professionals in developmental screening is particularly important, because of the greater emphasis placed on early identification of children with delays.

For instance, through well-child visits, health professionals have regular contacts with children 0 to 3 years-of-age, giving them the opportunity to monitor developments in children through periodic developmental screening (American Academy of Pediatrics, Council on Children with Disabilities (AAPCCD), 2007). The AAPCCD asserted that pediatric health care practitioners, in particular, play a key role in the identification, early intervention and subsequent referral of children with or at risk of developing disabilities.

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Newborn and child screening as a public health service, requires a broad social consensus support. Therefore, all stakeholders, including governments, health care providers, hospitals, clinicians, parent groups, and the public need to by consensus determine which disorders need to be added to the newborn-screening panels and the criteria to be used to decide on screening panels. This consensus development process should be premised on objective evidence-based assessments as well as sound ethical concerns.

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Newborn hearing screening, for instance, can be performed by volunteers, nurses, midwives, audiological technicians, audiologists, and other trained personnel. Initial training for those who perform newborn hearing screenings, as well as refresher trainings and periodic monitoring of staff performance, are essential to ensure quality screening. Studies have shown that on-going experience with screening is an important factor in maintaining low and accurate rates in hearing screening. (Minnesota State Statutes on Newborn Screening; (2014) Health. Chapter 144 section 144.966).

In Ghana the personnel responsible for the screening of infants and children for impairments and disabilities include the midwives, general nurses, community and public health nurses, general medical officers and paediatricians (anonymous).

According to the National Joint Committee on Learning Disabilities (2006), early identification as a process includes screening and examination for the presence of risk indicators as well as systematic observations and a comprehensive evaluation to establish whether or not a child has a disability or is at risk of developing one.

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The early years of life have been found to be critical to the overall development of children, particularly, those with disabilities as well as those at risk (National Joint Committee on

Learning Disabilities, 2006). The earlier a child is identified as having a developmental delay or disability, the greater the likelihood that the child will benefit from intervention strategies designed to compensate for the child's needs. According to Gorham and Stout (1995), with the present technology, at least 50% of all disabilities may be prevented or postponed if screening is done early to detect developmental delay for intervention.

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With regard to the time frame within which disabilities in neonates are detected, there are no established time limits. However the Centre for Disease Control and Prevention (CDC) is of the view that babies born in a hospital should be screened before they leave the hospital (CDC, 2011). Parents should take babies that were not born in a hospital and those that were not screened before leaving the hospital to a hospital or clinic for screening within a few days of birth.

In some States (in the USA) all babies are screened a second time, about two weeks after birth, and National Neonatal Screening Test (NNST) should be conducted for all babies who are between 5-8 days old (CDC, 2011). In the event that screening is performed late (i.e. after 8 days) it should be written clearly on the screening card proving reasons for not performing the screening within the usual time span. On some occasions, the laboratory will request repeat samples of what and for what reason(s). For example, if needed for confirmation of cystic fibrosis status, it is important for a repeat testing to be done between days 21-28 after the last test. It has also been recommended that repeat heel prick test should be undertaken when the baby reaches the equivalent of 36 weeks gestational age (Henley and Walker, 2007).

For babies born in hospital, two clinical neonatal screenings should be conducted before discharge. The first is done within 24 hours after birth and the second is carried out after a

few days. The reason for the first examination is to pick up abnormalities that may require prompt intervention and the second one aims at detecting abnormalities that may have been missed during the first screening. The second screening also helps to detect other abnormalities which may become apparent later in life as the fetal circulation of the newborn adapts to life outside the womb such as cardiac defects (Grosse et al., 2006). Grosse et al., (2006) in comparing the effectiveness of one versus two hospital neonatal screening, found that examining babies in hospital twice rather than once before discharge resulted in more congenital abnormalities being suspected. This could have resulted from more babies being examined by more experienced staff, because a second examiner might detect something that was missed at first or pick up new conditions that developed over a period (Grosse et al., 2006).

The study however revealed that the extra "diagnoses," did not lead to any appreciable increase in interventions that might improve infant's health nor did the infants from one group make extra use of emergency services. There was also no evidence that one examination was less effective than two in identifying babies who required medical attention. Although babies with suspected abnormalities underwent two instead of one hospital neonatal examination, the practice did not show any net health benefits in favour of the babies who had two examinations. A two screening policy does, however, carry additional resource implications for hospital services since more resources will be required for further screening. More than one screening also brought extra anxiety for parents whose children are wrongly suspected of having abnormalities (Grosse et al., 2006).

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Glazener et al., (1999) suggested that screening tests should be administered at the 9<sup>th</sup>, 18<sup>th</sup>, and 30<sup>th</sup> month visits. Because the frequency of regular pediatric visits decreases after 24 months of age, a pediatrician who expects that his or her patient will have difficulty attending a 30<sup>th</sup> month visit should conduct screening during the 24<sup>th</sup> month visit.

## 2.4 RESOURCES NEEDED FOR EARLY DETECTION OF DISABILITIES IN Formatted: Font color: Auto

### NEWBORNS AND CHILDREN

For newborn screening facilities to provide effective screening services, they must be resourced adequately with the right resources to guarantee good results. Reliable funding sources should be available for each system component such as follow-up, diagnosis, treatment, and information systems for monitoring screening outcomes. Education of parents and care providers and adequate reimbursement for genetic counseling and case management services are also needed if newborn screening is to live up to its promise (Grosse, 2006). And this can only be done if the facilities charged to perform the screening are provided with the needed resources.

A decision as to whether to provide a public health service to the entire population should be based on the premise of evidence of benefit, risk, and cost and with full consideration of public resources available and priority targets set. Regardless of whether universal newborn screening is funded by the public or the cost element is passed on to a third-party payer or the parents, the implications for resource allocation and the opportunity cost of foregone alternatives need to be considered. Resources could potentially be provided at the expense of access to other general health care services of demonstrated and proven benefits. Prioritization is also important when public health agencies offer other clinical services,

such as immunizations and cancer screening, to people who cannot otherwise afford them (Boyle, et al., 2005).

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There have been recommendations for the use of behavioral methods for assessing for impairment in young children in developing countries because of limited fiscal and technological resources to support more sophisticated screening tests (Gell, et al., 1992). For instance, two key developmental points have been recommended in the screening for hearing impairment among infants and young children in developing countries; the first prior to the attainment of age of 2 and the second at the time of school entry, to reduce the cost involved in conducting more hearing screening for infants and children (Gell, et al., 1992). Because screening approaches based on high technology may be impractical and too costly for developing countries, screening methods that are performance based, incorporating behavioral techniques, should be applied.

The caution, however, in the implementation of such screening approaches in developing countries is that, follow-up services should be established before implementing such screening methods. The validity of screening based on behavioral methods requires sensitivity to the use of specific stimuli that are relevant and appropriate in a given country and culture. A community based screening efforts should be geared towards drawing on trained health workers to visit homes and to carry out screening using checklists for families and simple screening tests (Gell et al., 1992). Careful assessments must also be made for other screening technologies such as deoxyribonucleic acid (DNA)-based screening that can reveal disorders or variants, for which the clinical implications may be well understood (Boyle et al., 2005).

2.5 CHALLENGES IN THE EARLY DETECTION OF DISABILITIES IN

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#### INFANTS AND CHILDREN

Screening for the identification of impairments and disabilities among infants and children face significant challenges, especially in developing countries, due to limited resources and qualified professionals to carry out the screening (Simeonsson, 1991). Limited resources have also made it difficult to make projections about the prevalence of disability in children. For instance, Simeonsson (1991), cited lack of simple and efficient screening tools as a major factor that restricts estimation of prevalence of disability in young children in developing countries.

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Due to the limited fiscal and technological resources, behavioral methods have been recommended for assessing hearing impairment in young children in developing countries (Gell et al., 1992).

The level of state resources available (personnel, equipment, service capacity); the program's interpretations of available evidence concerning given conditions (incidence, treatability, impact); the availability of new screening methodologies; and public advocacy by families, health care professionals or state legislators have often led to divergence among states regarding which conditions should be mandated for newborn screening. In turn, this divergence has resulted in significant disparities in screening services available to infants (Simeonsson, 1991).

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The public health system and new born screening, for that matter, face many challenges. There is limited health care service infrastructure resulting in a disconnect between primary care professionals and subspecialists, particularly in the rural areas. This problem is worsened by the number and variety of rare conditions identified during newborn screening programs. There are limitations in the availability of specific expertise for managing many

of the rare conditions. Therefore, considerable needs exist in the areas of training and education about the disorders detected through newborn screening programs throughout the health care (Simeonsson and McDevitt, 1999).

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Improvements in the newborn screening system and the expansion of the number of conditions for which screening is offered come with costs. These costs and the associated benefits seem to accrue independently of the public and private health care delivery systems thus making their integration difficult. Also, although for most screening policies, programs necessary to ensure that screening and diagnosis will occur are in place, they have limitation ensuring long-term management including the provision requisite treatment and services (Simeonsson and McDevitt, 1999).

The unavailability of standardized screening tools even in the developed countries is also a serious worry to practitioners. According to Sherman (2011), the use of standardized screening tools as recommended by the AAP is not a routine practice in most pediatric primary health care practices in certain states of the US.

The introduction of new technologies in newborn screening presents some challenges. The first is the expanding knowledge base of the etiology and therefore the treatment or potential treatment of genetic diseases. The rapid expansion of diverse technologies such as multiplex platforms that may be used in screening also presents as a challenge. The third challenge is the increased use of tiered testing strategies to enhance the positive predictive value of an initial abnormal result with its high cost element (Watson et al., 2006).

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The lack of newborn screening program uniformity for infants, the changing dynamics of emerging technology, and the complexity of genetics, require an assessment of the state of the art in newborn screening and a perspective on the future directions such programs could take (Watson et al., 2006).

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Limited funding, manpower shortages, inadequate support services, low public awareness and the uncertainty regarding the commitment from healthcare practitioners may present some challenges but these are not insurmountable. Pilot studies are necessary in each country to provide empirical data that will guide healthcare providers who wish to introduce such a programme at any level of healthcare delivery (Olusanyaa, 2003).

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Another challenge cited for neonatal screening for developmental delays is the limited ability of infant tests, whether intended for screening or definitive diagnosis of intellectual functioning, to predict future functioning and this has led to controversies concerning their use. Another challenge is inaccuracy of certain screening or diagnostic findings about disabilities. The use of the wrong kind of screening instrument could also pose a challenge to effective screening of neonates or newborns for disabilities. This is because the advantage of screening instruments is that they state their norms explicitly, serve as a reminder to the clinician to observe development, and are an efficient way to record the observations. When physicians or midwives use only clinical impressions, estimates of children's developmental status are often inaccurate (American Academy of Pediatrics, Committee on Children with Disabilities, 1993).

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Unavailability of appropriate referral centers and/or specialists is equally posing problems to the screening and early intervention in infant and childhood disabilities. Malloy et al., (2000) reported that care providers who work with young children with disabilities, other than deaf-blindness, are also struggling to get better ways to identify and provide services for children in need of early intervention. For instance, the standard practice for early detection of and intervention for hearing loss are; screening for hearing loss by age 1 month, audiologic evaluation by age 3 months, and enrollment unto appropriate intervention services by age 6 months. In the US, more than 95% of newborns are screened for hearing loss prior to hospital discharge with a reduction in the average age of identification from 24–30 months to 2–3 months. Unfortunately, many of these infants are not being enrolled in appropriate intervention services by age 6 months

(Morton & Nance, 2006; Joint Committee on Infant Hearing, 2007; Malloy, et al., 2000).

Accordingly, health professionals who do screening of newborns require continuous training to upgrade their knowledge on how to identify disabilities in newborns and also to know the appropriate intervention measures. This assertion is buttressed by Malloy et al., (2000), when they noted that early intervention in disabilities in children is the responsibility of specially trained health professionals who are mandated with the task of rendering early intervention in these disabilities.

Olusanya et al., (2004) observed that limited funding, manpower shortages, inadequate support services, low public awareness and the uncertainty regarding the commitment from healthcare practitioners may present some challenges to neonatal screening for disabilities, but these can be dealt with. According to Padilla (2008), establishing sustainable newborn

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screening programmes in developing countries poses major challenges as it competes with other health priorities like infectious disease control, immunization, and malnutrition.

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The reliance on informal community based identification of children with disabilities, which is mostly practiced in developing countries, is likely to yield substantial underestimation of disability prevalence in those countries. This is due to the fact that, stigma attached to disability may keep families from letting others know of their children's condition. Use of informal community identification could lead to missing children with less severe or hidden disabilities (Simeonsson, 1991).

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# CHAPTER THREE

## RESEARCH METHODOLOGY

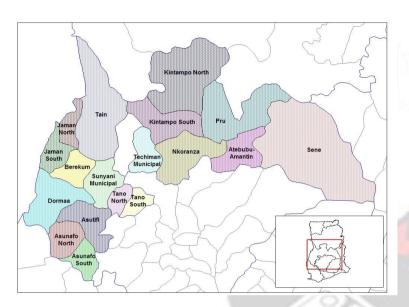
### 3.0 INTRODUCTION

This chapter discusses the methodology for the study and covers the following: research design, study area, study population, sampling technique and sample size, the research instruments, method of data collection, pretesting as well as ethical considerations.

# 3.1 Study Area

Figure 2: Map of the Brong Ahafo Region

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The study was conducted in selected health facilities in the Brong-Ahafo Region. The region is located in mid-western Ghana and between the Ashanti Region and the Northern Region. The region is the second largest in Ghana and covers an area of 39,557 square kilometers. It shares boundaries with the Northern Region to the north, the Ashanti and Western Regions to the south, the Volta Region to the east, the Eastern

Region to the southeast and La Cote d'Ivoire to the west. The region is divided into 27 administrative districts with Sunyani as its capital.

## Population

The Brong Ahafo Region has an estimated population of 2,310, 983 accounting for approximately 9.4 percent of Ghana's population. With a land size of 39,554 km<sup>2</sup>, the

population density for the region has increased from 45.9 persons/km<sup>2</sup> in 2000 to 58.4 persons/km<sup>2</sup> in 2010 (Ghana Statistical Service (GSS), 2012)

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Although the prevalence of disability in the region is lower compared to other regions, it is said to be in the increase. The most common disabilities in the region include those related to sight, hearing and speech, physical, intellectual and emotional. There are also persons with multiple disabilities (GSS, 2012).

The number of Persons with Disabilities (PWDs) in the region was 54,038 constituting 2.3 percent of the regional population. The male to female ratio was 11: 12 while urban to rural ratio was 10: 13. The proportion of PWDs in Brong Ahafo region decreases with age, thus, people less than 15 years have the least proportion of PWDs (1.19%) (GSS, 2012).

### State of Health Facilities in Brong Ahafo

The region has about 25 hospitals, 35 health centers, 106 rural clinics, and 54 maternity homes. More than half of all the health facilities in the region are owned by Government, that is, all health centers, and two-thirds of rural clinics. Three-quarters of hospitals (excluding health centres, clinics and maternity homes) and almost all maternity homes, however, are privately owned. Most of the private hospitals, notably the mission hospitals, have government-paid/seconded personnel (GHS Annual Report, 2006).

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Traditional healers and healing facilities are widely distributed throughout the region and are more accessible to especially, the rural population than all the other facilities. Over 90.0 per cent of localities in Kintampo, Atebubu, and Sene districts have traditional healers.

Berekum has the lowest proportion, with about 38.0 per cent of localities having traditional healing facilities, while the rest have more than 50.0 per cent (GHS Annual Report, 2006).

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The Sunyani municipality has the highest of health concentration of facilities with a quarter of all the hospitals in the region. The only district that has no hospital is Sene, while Jaman has the highest number of rural clinics and maternity homes. Although it is not possible to have a health facility in every community, the available facilities in the region fall short of the recommended standards with regard to the spread. Meanwhile, the Health Ministry recommends a distance of eight kilometres of a facility from a locality (GHS Annual Report, 2006).

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It is easy to access clinics than hospitals in terms of distance due to a stock of these facilities in the region. Apart from Kintampo, Atebubu and Sene, which have less than 40.0 per cent of localities within a 10-kilometre radius of a clinic, the remaining districts have more than 50.0 per cent of localities living within a 10-kilometre radius of a clinic (GHS Annual Report, 2006).

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There is a serious shortage of personnel providing direct health service, with pharmacists being the worst affected (50.0%), nurses (21.5%) and doctors (17.6%). This shortage in health service providers will lead to loss of confidence in orthodox health care (GHS Annual Report, 2006).

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Fertility and child survival: the most urbanised districts, Sunyani and Berekum, have the least fertility rates, while Sene and Asunafo which are more rural, have the highest fertility

levels. Asutifi and Atebubu are other districts with relatively higher fertility rates. So far the three Demographic and Health Surveys conducted in Ghana (1988, 1993 and 1998) have confirmed that urban woman have lower fertility indicators than rural women, and also that the higher educational level of women, the lower the fertility indicators (GHS Annual Report, 2006).

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The region has a child survival rate of 82.3 per cent, implying that less than 16 per cent of children born to women (12-49) years died. Survival rates for the districts range from 79.8 per cent in Wenchi to 85.1 per cent in Asunafo. This implies that child survival rate in the region is high (GHS Annual Report, 2006).

**Disability Situation**: It is estimated that about 54,038 (2.3%) of the region's population have disabilities with a <u>malea male</u> to female ratio for PWDs of eleven to twelve.

The regional capital Sunyani Municipal, Pru and Nkoranza South have the highest proportion of more than three percent of PWDs while Nkoranza North, Sunyani West, Atebubu Amantin and Kintampo South reported the lowest proportion of less than two percent PWDs.

Types of disabilities recorded in the census include sight, hearing and speech, physical, intellectual and emotional. Disability cases can be multiple, that is, one person can have more than one type of disability.

The proportion of PWDs in Brong Ahafo region decreases with decreasing age. Thus, people less than 15 years have the least proportion of PWDs (1.19%).

——— (Ghana Population and Housing Census (GPHC) report, 2010).

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### 3.2 STUDY POPULATION

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The target population for the study consisted of medical superintendents/directors of hospitals, nursing service administrators/matrons, midwives, public/community health nurses, medical officers (paediatricians) and laboratory technologists from selected health facilities in the region. The selected health facilities included the Sunyani municipal and regional hospitals, Goaso municipal hospital, Kintampo municipal hospital, the Saint Theresa's hospital Nkoranza, Saint Elizabeth's hospital Hwidiem, Holy Family hospital Techiman, Presbyterian hospital Dormaa- Ahenkro and the Methodist hospital Wenchi. These health facilities were selected because they span across the various geographical locations of the region and also have similar characteristics as others in the region and therefore representative of these health facilities. Most of the respondents (61%) were working in public hospitals 26% in private hospitals, and about 13% in clinics.

# 3.3 RESEARCH DESIGN

The study design was descriptive and utilized questionnaires to collect data on the capacity of health facilities to detect impairments and disabilities in newborns and

children. Fraenkel and Wallen (2000) observed that the purpose of descriptive research is to observe, describe and document aspect of phenomenon as it naturally occurs.

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According to Glass and Hopkins (1984), descriptive research can be either quantitative or qualitative. It can involve collections of quantitative information that can be tab ulated along a continuum in numerical form, such as scores on a test or the number of times a person chooses to use a —certain feature of a multimedia program, or to describe categories of information such as gender or patterns of interaction when using technology in a group situation.

Descriptive research involves gathering data that describe events and then organizing, tabulating, depicting, and describing the data collected. It often uses visual aids such as graphs and charts to aid the reader in underst anding the data distribution (Glass and Hopkins, 1984).

The researcher made use of descriptive research because it is easier and more cost effective to use. The second reason is that with descriptive research, graphs and charts are used aiding better understanding of the data distribution.

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# 3.4 SAMPLE SIZE

In all hundred (100) participants from ten (10) selected health facilities across the Brong Ahafo region were enrolled for the study. This was made up of ten (10) par ticipants from each of the ten selected facilities. The participants comprised medical directors/superintendents; nursing administrators/matrons; medical officers, nurses and midwives working in the maternity, labour and paediatric wards; paediatricians;

biomedical scientists/laboratory technologists of the selected health facilities. For each of the selected health facilities, the medical director, the matron/nursing administrator, the head of the medical laboratory, two midwives or nurses each from the labour/maternity ward, paediatric ward, and the maternal/child and reproductive health unit were selected for the study. One paediatrician or medical officer each at the paediatric consulting room and/or at the paediatric wards from each selected health facility was also included. These health professionals were selected because they were either directly involved in the care of infants and children or carry out services that can facilitate the detection of defects or disabilities in children.

# 3.5 SAMPLING TECHNIQUE

Districts were selected using random sampling technique, while cluster sampling technique was used to select the health facilities. In the case of selecting participants from the selected health facilities, purposive sampling technique was employed.

In selecting the districts, first, the 27 districts in the region were assigned numbers 1 to 27 and put in a container. The elements were mixed up and 9 picked out of the container at random. facilities in each of the districts written out and put in 9 different containers and labeled

Secondly, the sampled districts were noted and the names of all the health D. Simple random sampling was used to select health facilities in each of the groups. This technique was chosen because the elements in the each group were homogeneous. This implies that the elements in each group had similar characteristics and provides similar services. Nine containers were assigned letters, A, B, C, D, E, F, G,

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Commented [OI2]: Why cluster? How was this done?

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H, and I. Container A contained elements in group 1, container B had elements in group

2, container C had elements in group 3, in that order up to the last, container I containing

Commented [OI3]: ???????? but I though you said you used cluster sampling? Which is which?

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elements in group 9. The regional hospital was purposively sampled for the research due to its strategic importance as the regional referral centre.

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The elements in each of the containers were mixed up to give each health facilities equal chance of being selected. An assistant was blindfolded and asked to pick one element from each of the containers. Upon picking the health facilities from which the health personnel were sampled, a purposive sampling was used to sample the health personnel hospital directors, nursing administrators, midwives and nurses, paediatricians, and laboratory technologists. The researcher used a purposive sampling because he wanted to target a particular group of health personnel - health personnel who attend to babies and children at the health facilities. These were people who could provide the required information due to their expertise and the services they render.

Commented [OI5]: This does not indicate cluster sampling

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## 3.6 RESEARCH INSTRUMENT(S)

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Data for this study were obtained through two data sources: primary data sources and secondary data sources. The secondary data sources included internet sites and published works dwelling on the subject of interest. The secondary data were used to review literature on the subject of study. The primary data were obtained from respondents through the administration of structured questionnaires at the selected health facilities sites.

### 3.7 METHOD OF DATA COLLECTION

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The data used for the study were collected personally by the researcher. Consent was sought from the respondents before administering the question. The average time taken by respondents to complete the questionnaire was 30 minutes.

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Hundred (100) questionnaires were distributed out of which eighty (80) were retrieved. The questionnaire covered the socio-demographics of respondents, early disability detection practices, personnel involved in screening of infants and children, time frame for detecting disabilities in newborns, resources needed for screening for disabilities in children, challenges faced in the screening for disabilities in babies and children and recommendations for improving the screening process in health facilities.

3.8 PRETESTING Formatted: Font color: Auto

The data collection tools were pretested in some health facilities in the Ashanti Region. It ensured that questionnaire items were clearly written and ambiguities that might have made it difficult for respondents to answer the questions eliminated. The pilot test therefore increased the reliability and validity of the data collection instrument.

3.9 DATA ANALYSIS Formatted: Font color: Auto

The analysis of the collected data was done using Statistical Package for Social Sciences (SPSS) software. The data collected were summarized into tables, graphs and charts for easier understanding.

3.10 ETHICAL CONSIDERATIONS

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Clearance was obtained from the Committee on Human Research, Publications and Ethics (CHRPE) at the Kwame Nkrumah University of Science and Technology (KNUST).

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Permission was also obtained from the Brong Ahafo Regional Director of Health Services to undertake the study in the selected health facilities.

Prospective participants were given the questionnaires and consent forms to read through carefully and all their questions and/or concerns about the study addressed. They were then made to sign the consent form to indicate their consent to participate in the research before completing the questionnaires.

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In addition, the anonymity and confidentiality of all participants were ensured by not including or demanding the identity and/or any incriminating information on them; only group information, without identifiers, has been reported and not individual responses. The participants were also informed of their right to withdraw from the study without jeopardizing their relationship with the principal investigator or anybody.

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# RESULTS OF STUDY

# 4.0 INTRODUCTION

This chapter presents the results from the study, discussed under the following subsections: background information on respondents, early detection practices, personnel and their skill mix for early detection of disabilities, screening schedules, challenges in early detection of disabilities, recommendations for improving on disability detection rate in infants and children.

#### 4.1 ANALYSIS OF DATA

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#### 4.1.1 Background Information on Respondents

**Table 4.1 Gender of respondents** 

Sex	Frequency	Percent
Male	30	37.5
Female	47	58.8
No response	3	3.8
Total	80	100.0

Source: Field work, 2012

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From Table 4.1, it can be seen that the male respondents to the questionnaire comprised approximately 38% while the females made up about 59% of the respondents. However about 4% of the respondents did not respond to the question on gender for reasons not known to the researcher. The dominance of the females, as indicated in the result, may be due to the fact that the largest professional groupings in the health profession in Ghana are the nurses followed by the midwives which are predominantly females.

**Table 4.2 Job Designation and Profession of Respondents** 

	1500	1 months	
Job Designation	Frequency	Percent	Formatted: Justified
Medical Director	1	1.3	Formatted: Justified
Nursing Administrator	11	13.8	Formatted: Justified
Doctor	10	12.5	Formatted: Justified
ward incharge	4	5.0	Formatted: Justified

Biomedical scientist	7	8.8	Formatted: Justified
general nurse	21	26.3	Formatted: Justified
laboratory Technician	3	3.8 ←	Formatted: Justified
physician Assistant	4	5.0	Formatted: Justified
Staff Midwife	7	8.8	Formatted: Justified
Midwifery	7	8.8	Formatted: Justified
Community H N	2	2.5	Formatted: Justified
No response	3	3.8	Formatted: Justified
_			
Total	80	100.0	Formatted: Justified
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Profession			
Medical Doctor	6	7.5	Formatted: Justified
Midwife	22	27.5	Formatted: Justified
General nurse	24	30.0	Formatted: Justified
Laboratory technician	3	3.8	Formatted: Justified
Laboratory Biomedical	9	11.3	Formatted: Justified
scientist			
Ophthalmic nurse	3	3.8	Formatted: Justified
	6	7.5	Formatted: Justified
Physician Assistant			
Community H N	7	8.8	Formatted: Justified
Total	80	100.0	Formatted: Justified
Source: Field work, 2012		1	
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From Table 4.2, it can be observed that general nurses were the highest comprising of 26 %, followed by nursing administrators (14%). The least were the medical directors (1.3%), laboratory technicians (3.8%), physician assistants (5%), and community health nurses (2.5%), who constituted between 1 and 4 percent of the sampled population.

On the professional background of the respondents, general Nurses were the highest, comprising 30%, while the least professionals were ophthalmic nurses and laboratory technicians, each representing approximately 4% of the respondents.

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		of cilities for	Maternal ol family medic	ostetrical and al history	_
Response	early detecti Frequency	Percent	Frequency	Percent	=
Very capable	14	17.5	34	42.5	<u>=</u> -
Capable	30	37.5	36	45.0	
Not Sure	26	32.5	5	6.3	4.1.2
Less capable	3	3.8	3	3.8	Early
No response	7	8.8	2	2.5	
Total	80	100.0	80	100.0	J

Detection Practices Formatted: Font color: Auto

Table 4.3 Capacity for detection and use of maternal obstetrical/family medical history

3.02.1

Source: Field work, 2012

As shown in table 4.3, when respondents were queried on their respective facility's capability to detect disabilities early in children, about 4% of the respondents thought their facilities did not have the capacity for early detection of disabilities in children while about one-third (33%) were not sure. However, more than half (55%) of them reported that their facilities capable of early detection of disabilities in newborns and children. About 9% of the respondents did not respond to this question probably because they were unable to evaluate their facility's ability to perform this function.

Most (87.5%) of the respondents said they were capable of using maternal obstetrical and family medical history as an early detection practice to help in assessing the risk of a mother at giving birth to a child with impairments. A few (4%), thought they were less capable in using maternal obstetrical and family medical history to predict disability of

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the unborn with 6 % of the respondents not being sure if the practice was used in their facilities.

Table 4.4 Mandatory screening, physical examination and physical assessment of newborns

of of newborns

Physical examination Physical assessment of Formatted: Justified

for

newborns

	newborns		defects/disabilities			
Responses	Frequency	Percent	Frequency	Percent	Frequency	Percent
Very capable	20	25.0	47	58.8	32	40.0
Capable	24	30.0	25	31.3	26	32.5
Not Sure	17	21.3	0	0	15	18.8
Less capable	13	16.3	4	5.0	3	3.8
Not capable	2	2.5	0	0	0	0
No response	4	5.0	4	5.0	4	5.0
Total	80	100.0	80	100.0	80	100.0

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Source: Field work, 2012.

Mandatory

screening

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From table 4.4, it can be seen that more than half (55%) of the respondents reported that their facilities undertake mandatory screening of newborns for various forms of disabilities while about 19% of them responded in the negative.

It can also be seen from Table 4.4 that 90% of the respondents said the facilities were capable of facilitating physical examination of newborns and infants. This suggests that most (90%) of the respondents agreed to this practice, suggesting that it is a generally upheld practice in the health facilities.

A majority (73%) of the respondents said their facilities were capable of using physical assessment to detect defects or disabilities in newborns and infants. This assessment is done after examination to verify the disability status of newborns.

Source: Fieldwork, 2012

Responses	<b>Brazelton Assessment</b>		Ap	gar score	
	Freque	ncy Percent	Freque	ncy Percent	Table 4.5 shows
Very capable	8	10.0	49	61.3	the responses on
Capable	15	18.8	15	18.8	the use of
Not Sure	26	32.5	9	11.3	D 1
Less capable	13	16.3	0	0	Brazelton and
Not capable	3	3.8	0	0	Apgar assessment
No response	15	18.8	7	8.8	tools. On the use
Total	80	100.0	80	100.0	of Brazelton

#### Table 4.5 Used Appar and Brazelton Assessment

Assessment tool, 29% said they were capable of using it to screen newborns while 32.5% were not sure. The rest disagreed suggesting that the usage of Brazelton may not be a very common practice.

However, the use of Apgar score seemed to be common as about 80% of respondents-reported being capable of using it.

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	Assess developmen		motor Undertake anthropomet measurements				
Response	Frequency	Percent	Frequency	Percent			
Very capable	25	31.3	15	18.8			
Capable	25	31.3	31	38.8			
Not Sure	15	18.8	22	27.5			
Less capable	7	8.8	4	5.0			
No response	8	10.0	8	10.0			
Total	80	100.0	80	100.0			

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Source: Field work 2012

Responses from the respondents suggest that assessment of motor development and neurological status of newborns and children seemed to be a common practice. This is because most (62.6%) of the respondents reported being capable of assessing the motor development and neurological status of newborns and children (see Table 4.6).

	Vital signs		Monitor special senses		
- 1	Frequency	Percent	Frequency	Percent	
Very capable	47	58.8	28	35.0	
Capable	11	13.8	26	32.5	
Not Sure	5	6.3	11	13.8	
Less capable	4	5.0	7	8.8	
No response	13	16.3	8	10.0	
Total	80	100.0	80	100.0	

However, as shown in the table, just about half of the respondents (57.6%) reported that they were capable of undertaking anthropometric measurements of newborns. Some respondents (28%) were unsure with 10% not responding not responding to this question probably because they could not assess their health facilities' ability to carry out this assessment on newborns or they were not aware of the existence of these practices.

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Source: Field work, 2012

On monitoring for vital signs for deviations, as much as 72.6% reported that they were capable of undertaking the practice (see table 4.7). Similarly, the assessment of special senses seemed to be common as approximately 68% claimed they were capable of undertaking such practice.

Table 4.8 Assessing newborns for signs of prematurity, hormonal disorders and

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## prenatal inutero defects

	Assess for signs of Biochemical screening Procedures to detect						Formatted: Justified, Line spacing: Multiple 1.15 li
	premat	urity	for hormo	nal disorder	s prenatal	in-uter	0
					defects e.g.	Chorionic	c
					villi sampli		-
Response	Freque	ency Percent	Frequenc	y Percent	Frequency	Percent	Formatted: Justified, Line spacing: Multiple 1.15 li
Very capable	48	60.0	18	22.5	6	7.5	
Capable	11	13.8	10	12.5	6	7.5	Formatted: Justified, Line spacing: Multiple 1.15 li
Not Sure	9	11.3	17	21.3	26	32.5	
Less capable	0	0	31	38.8	22	27.5	
Not capable	0	0	4	5.0	12	15.0	
No response	12	15.0	0	0	8	10.0	
Total	80	100.0	80	100.0	80	100.0	

Source: Field work, 2012

Table 4.8 shows assessment of newborns for signs of prematurity, and biochemical and inutero screening for defects. It can be seen from the Table that as much as 73.8% of the respondents reported being capable of assessing newborns for signs of prematurity. This suggests that the assessment for prematurity is done by majority of health professional in

the various health facilities across the region. However, biochemical screening for hormonal disorders appears to be uncommon as just 35% were practicing it.

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Procedures to detect prenatal defects in utero were also not common because only 15% of the respondents claimed they were capable of undertaking these procedures. The large proportion of the respondents were unsure, especially of undertaking procedures to detect prenatal intrauterine defects probably due to the fact that it is not commonly practiced in health facilities in the region.

# 4.1.3 Personnel and Their Skill Mix for the Early Detection of Disabilities

Table 4.9 Personnel responsible for the early detection of disabilities

Frequency	Percent
6	7.5
10	12.5
35	43.8
16	20.0
4	5.0
2	2.5
4	5.0
3	3.8
80	100.0
	6 10 35 16 4 2 4

Source: Field work, 2012

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When asked about the personnel responsible for the early detection of impairments and disabilities in infants and children, 44% said it was the responsibility of midwives, 20% mentioned general nurses and 13% mentioned medical doctors. Very few respondents thought that it was the responsibility of paediatricians, physiotherapists, audiologists or laboratory technicians to detect defects and disabilities in inf ants and children. Although midwives were the most cited health professionals for the early detection of disabilities in newborns, probably because they assist deliveries and spend more time with the newborns or infants, the responses seemed to suggest dis agreement among respondents on who is responsible for the early detection (see table 4.9).

## 4.1.4 Requisite Skills in Early Detection of Disability

Table 4.10 Possession of skill to detect musculoskeletal, neurological and chromosomal defects

-	Musculoskeletal			N		Chromosomal defects		
	defects		Neurologic	al defects	Chromosor	nal def <del>ects</del>	Formatted: Justified	
Response	Frequency	Percent	Frequency	Percent	Frequency	Percent	Formatted: Justified	
Strongly Agree	53	66.3	38	47.5	36	45.0		
Agree	8	10.0	20	25.0	26	32.5 •	Formatted: Justified	
Not sure	0	0	2	2.5	7	8.8		
Disagree	10	12.5	9	11.3	2	2.5		
Strongly disagree	5	6.3	7	8.8	5	6.3		
No response	4	5.0	4	5.0	4	5.0		
Total	80	100.0	80	100.0	80	100.0	/3	

Source: Field work, 2012

With respect to whether respondents possess the requisite skills to detect musculoskeletal, neurological and chromosomal def ects in children, the results suggest that majority of the respondents indicated they had these skills. As shown in Table 4.10, Formatted: Font color: Auto

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most of the respondents (76%) claimed they had the requisite skill to detect musculoskeletal defects in newborns and infants. A lso 73% had the skill to detect neurological defects in newborns and infants, and 78% had the requisite skill to detect chromosomal disorders.

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 $\underline{\textbf{Table}} \ \underline{\textbf{4.11 Have requisite skill to detect visual, hearing and chromosomal disorders}}$ 

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in infants and children

	Visual impairment		Hearing	impai <mark>rment</mark>	Metabolic disorders	
Response	Frequency	Percent	Frequenc	y Percent	Frequency	Percent
Very capable	35	43.8	30	37.5	10	12.5
Capable	16	20.0	13	16.3	23	28.8
Not Sure	10	12.5	9	11.3	27	33.8
Less capable	7	8.8	16	20.0	12	15.0
Not capable	8	10.0	8	10.0	3	3.8
No response	4	5.0	4	5.0	5	6.3
Total	80	100.0	80	100.0	80	100.0

Source: Field work, 2012

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Table 4.11 above presents responses on whether or not respondents are capable of detecting visual, hearing and chromosomal disorders in infants and children. As seen in the table about 64% of the respondents reported they had the requisite skills to detect visual impairment in the infants and children whereas 12.5% were not sure. Also, more than half (54%) of the respondents claimed they had the requisite skills to detect hearing impairment. With respect to the detection of metabolic disorders in infants and children , 41.3% reported of having the requisite skills while as many as 34% were not sure of having s uch a skill. This finding may be due to the fact that metabolic screening for inborn errors is an advanced procedure that requires the use of some advanced laboratory equipment.

## 4.1.5 Screening Schedules

Table 4.12 Commencement of newborn screening and detection time

	Commence	ment	of Detec	ction of impairn	nent i
	screening of	f newborns	s newb	orns	
Time after birt	h Frequency	Percent		Frequency	Percent
1hour	39	48.8	30		37.5
24 - 48 hours	15	18.8	17		21.3
72 hours	0	0	6		7.5
1 week	9	11.3	8		10.0
After 1 week	4	5.0	0		0
No response	13	16.3	19		23.8
Total	80	100.0	80		100.0

Source: Field work, 2012

From table 4.12, it can be seen that nearly half of the respondents (49%) said that screening for health problems in newborns is commenced in the first hour after birth while 19% said it is commenced within 24 - 48 hours. This suggests that screening is done in most hospitals within 48hrs after birth. The responses also suggest that there is no uniformity in the screening schedule for defects in newborns in the health facilities across the region as some respondents indicated that it is done within one week (11.3%) and after one week (5%).

On the time frame within which disability is detected, about 38% of respondents said it is detected within the first hour, 21% said within 24 – 48hrs, 7.5 % said 72 hours and 10 % said within 1 week after birth.

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Table 4.13 Available resources

Response	Frequency	Percent	
Skilled health personnel	48	60.0	
Modern technology	8	10.0	
Screening tests	7	8.8	
No response	17	21.3	
Total	80	100.0	

Source: Field work, 2012

On the availability of resources to facilitate screening and detection of disabilities in infants and children, skilled health personnel was the most cited resource (60%-) while screening tests was the least cited (8.8 %) (See Table 4.13). For reasons unknown to the researcher, 21.3% of them did not respond to this item.

# 4.1.6 Challenges in Early Detection of Disabilities

**Table 4.14 Challenges in Early Detection of Disabilities** 

Challenge	Yes	Percentage
Lack of skilled personnel for early detection	34	42.5
Lack of specialized technology/equipment	73	91.3
Lack of screening tools	59	73.8
Inability to detect hidden disabilities or defects	42	52.5
Parents killing babies after abnormalities are detected	23	28.8
Lack of funds	46	57.5
Lack of specialists for onward referral for further	22	27.5
treatment		

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Table 4.15 Recommen	ndation	ıs to impro	ove detection		-	

Table 4.15 Recommendations to improve detection			Formatted: Font color: Auto
Recommendation	Frequency	Percent •	Formatted: Justified
Construction of a special unit for detecting disabilities in	2	2.5	Formatted: Justified
children			
Education of mothers/parents on signs of disabilities.	7	8.8	Formatted: Justified
Acquiring modern equipment to help detect disabilities	19	23.8	Formatted: Justified
Educating the general public	1	1.3	Formatted: Justified
Training specialists (pediatrician) for disability detection	5	6.3	Formatted: Justified
Pregnant women should be encouraged to take antenatal	8	10.0	Formatted: Justified
care seriously			
More training should be given to in-service personnel	3	3.8	Formatted: Justified
Provision of enough screening tools and modern equipment	9	11.3	Formatted: Justified
for every unit/facility	1		
Health Education for parents to effectively manage infants	2	2.5	Formatted: Justified
with disabilities			
Creation of a unit for early detection and treatment of	10	12.5	Formatted: Justified
disabilities	7	2	
Workshops should be organized to address disability issues	1	1.3	Formatted: Justified
and abreast professionals with knowledge			
No response	13	16.3	Formatted: Justified
Total	80	100.0	Formatted: Justified

Source: Field work, 2012

screening and detection of disability in infants and children. As expected, the provision of modern screening equipment was the most recommended issue (24 %), while the least recommended issues were educating the public and organizing workshops for staff on

Table 4.15 above summarizes recommendations by the respondents for improving

screening for disabilities in children.

#### 4.2 CONCLUSION

This chapter presented the findings from the study. The findings indicated some health facilities had the capacity to facilitate the early detection of disabilities in children using various screening tools such as mothers' obstetrical and family history, physical examination/assessment, Brazelton assessment tool and Apgar score, neurological and motor assessment, assessing vital signs, monitoring the special senses, assessing for prematurity and hormonal disorders and doing intrauterine screening.

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Generally, the health facilities had adequate human resource with the right skill mix to facilitate effective screening and detection of disabilities in infants and children. This notwithstanding, lack of modern screening equipment was hampering efforts at early detection of disabilities in children and infants.

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It was recommended among other things that adequate screening equipment should be procured for the various health facilities in the region to improve on their detection rate, children screening units for mandatory screening of newborns and all children be established in health facilities, and compulsory screening of newborns and children for disabilities should be made part of the postnatal services.

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**DISCUSSION OF STUDY FINDINGS** 

5.0 INTRODUCTION

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**5.2 Early Detection Practices** 

This chapter discusses the findings of the study, laying emphasis on key observations and

responses. The findings are discussed under the following general subsections: existing

practices for disability detection, early detection practices, personnel and their skill mix for

early detection of disabilities, screening schedules, challenges to early detection and

recommendations.

**5.1 Background Information on Respondents** 

5.1.1 Job designation and Profession of respondents

The study revealed that general nurses and midwives together constituted the largest health

professionals. They are also considered to possess the requisite skills for early detection of

disabilities in children. Due to their large numbers in the health delivery system in the

region, it presupposes that the general nurses and midwives have a huge stake in the

screening and early detection of disability in newborns and children. This finding is in line

with the assertion by Boyle et al., (2005) that Pediatricians and midwives conduct most of

the physical examination on the newborn child to determine if the child has a defect or

not. Additionally, the Minnesota State Statutes on Newborn Screening states that screening

of Newborn is mostly performed by volunteers, nurses and midwives (Boyle et al., 2005).

Therefore, for the success of any programme aimed at facilitating effective screening and

early detection of disabilities in infants and children, the role of nurses and midwives

should not be ignored.

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5.2.1 Capacity for detection

The findings of the study

suggest that health facilities in

the region have the capacity to facilitate the early detection of

impairments or disabilities in

and children. infants

finding is somewhat unexpected

in view of the fact that many

health facilities lacked

resources to effectively perform

this function. Probably,

respondents felt that their health

facilities had the capacity

because some disabilities are

physical and obvious and can

easily be detected through

observation using basic tools.

This finding is thus inconsistent

with observations by Cole and

Flexer, (2006) that although the

overall health delivery system in

some developing countries has

gradually improved, a lot of

questions still arise concerning

the capacity of the various

62

health facilities to facilitate the early detection of "abnormal" conditions in children. about 85% of the respondents agreed that as part of their

According to (Cole and Flexer, 2006), health facilities can boost their capacity for detection of disabilities in children, if the referral system is effective and they are well equipped with the appropriate resources such as skilled health personnel who can perform screening in newborns and children, screening equipment/tools, and funds (Cole and Flexer, 2006). However there are no referral centers in the entire region equipped with the requisite resources to facilitate early detection and intervention of disabilities in children.

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disabilities, they took maternal
obstetrical and family medical
history of expecting

It should be noted that although the health facilities may lack the capacity to detect disabilities in children, many of them engaged in early detection practices. For instance, mothers. This is aimed at identifying mothers at risk of giving birth to children with impairment due to obstetrical complications or familial predisposition. Waechter et al (1985) observed that screening for early detection often begins with the taking of obstetrical history of the mother (information on pregnancy, immunizations, labour and delivery), use of medications, exposure to infectious diseases or environmental toxins and the trimester within which any problems occurred. It is important to consider these factors because they place the unborn child at risk of problems which can be identified through a detailed obstetrical history taking.

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Moreover, the findings showed that approximately 55% of the respondents agreed that they undertook mandatory screening of newborns for impairments or defects. This screening according to studies is important as it helps to identify children with disabilities; it helps to determine if additional evaluation is required and in what developmental domains (Hardman et al 1990).

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Johnston et al (2003) advocated that a brief examination of the baby should be carried out immediately after delivery to confirm the sex and identify any visible abnormalities such as spina bifida, cleft lip, cleft palate, or talipes equinovarus and to identify conditions requiring urgent attention such as anal atresia, which may not be immediately obvious. The research findings suggest that this practice seemed to be common in health facilities in the study area as many respondents reported that they physically examined and assessed newborns as part of the mandatory screening to detect defects in newborns.

The use of physical examination is a common screening practice probably because it is easier to use, less time consuming, and cheaper; it does not require the use of advanced technology. This method of screening, though simple and easy to conduct, does not promote a high detection rate because of its superficial nature. Johnston et al (2003) observed that physical examination is mostly a systemic (general) review of the body, and may not be able to identify concealed defects, which may lead to under detection of disabilities in newborns and children. This finding is supported by the assertion by AAP (2002) that existing detection rates of developmental disorders are lower than their actual prevalence in developing countries, which suggests that the challenges to early identification of children with developmental disorders have not been overcome especially in health facilities in non-industrialized countries.

#### 5.2.2 Use of Apgar and Brazelton assessment tools

The findings showed that the use of the Apgar score assessment tool is a common practice in health facilities across the region because almost three quarters of the sampled population admitted using it as an assessment tool for early detection of impairments in newborns. Apgar assessment tool is administered to newborns between one and five

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minutes after delivery (Apgar, 1953). Although the Brazelton neonatal behavioural assessment scale is a popular assessment device with a long and valuable history (Brazelton, 1990), the findings from the study showed that it is not a commonly used in heath facilities in the region. This may be due to the fact that health personnel in the region have not been trained on the said tool and therefore do not have the skill to apply it in the assessment of newborns for impairments with the potential of developing to disabilities.

5.2.3 Assessment of motor and neurological development and anthropometric

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#### measurement

About half of the respondents agreed that they assess the motor and neurological development of newborns and children for impairments and disabilities. This suggests that assessment of motor and neurological development of infants and children is a common practice in the various health facilities.

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Waggle (1996) cited assessment of the motor activities of neonate as a useful tool in screening for neurological disabilities. A reduced sensual or motor response could indicate a neurological or motor defect with the potential of leading to mental retardation, mobility and sensual impairments in the future. These tools are therefore very important in detecting defects in newborns and children. The study finding that this tool is commonly used in health facilities is, therefore, encouraging and should be encouraged and improved upon to facilitate the early detection of impairments and disabilities in infants and children.

#### 5.2.4 Monitoring of vital signs and special senses for deviations

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The monitoring of vital signs is a routine practice undertaken by nurses on patients for determining any form of deviation in their condition. It is also a basic screening tool to

assess the conditions of newborns, infants and children. Thus, the finding that this practice is common in health facilities in the region is expected.

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More than half of the respondents also reported employing the monitoring of the special senses of newborns and children in order to detect deviations in these organs. The special senses include hearing, sight, taste, smell, and touch. Through the assessment of the functions of these organs, one is able to detect if there is a problem that could lead to permanent disability like blindness or hearing impairment. In line with this finding, Waechter et al (1985) reported that assessment of the special senses, for example, assessing baby's eyes for visual impairment, and ears for hearing impairment, constituted some of the screening tools or procedures used for neonatal, infant and child screening in the neonatal units.

#### 5.2.5 Assessing newborns for signs of prematurity, hormonal disorders and prenatal

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#### inutero defects

The finding indicated that assessment of newborns for prematurity seemed to be a wide spread practice among the selected health facilities. This may be due the fact that prematurity of newborns can easily be determined through basic physical assessment or observation. It does not require any sophisticated tools or equipment and can be conducted by most health personnel like nurses and midwives with minimal training. However, biochemical and inutero prenatal screening for defects seemed uncommon probably because they are complex and require well equipped laboratories.

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According to Dworetzky (1996), amniocentesis a process which involves examining the chromosomes of the fetus within the mother is done by inserting a hallow needle into the

woman's abdomen and drawing out some of the amniotic fluids that surrounds the fetus. Chorionic villi sampling is another technique where fetal cells are removed through the birth canal with the use of a needle at about the tenth week of pregnancy (eight weeks since conception). Although these investigations are useful in detecting chromosomal disorders in the foetus the procedure is complex and required advanced equipment that may not be available in health facilities in the region.

5.3 Personnel and their Skill Mix for the Early Detection of Disabilities in Infants

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and

Children

The findings indicated that most of the respondents had skills to assess and detect musculoskeletal, neurological and chromosomal disorders in newborns and infants. However, assessment of neurological and chromosomal defects seemed to be low. This is probably due to the fact that while musculoskeletal defects can easily be identified thorough physical examination, detection of neurological and chromosomal disorders requires advanced equipment. Thus, although health professionals in the region may have the skill to detect these defects, they may not have the requisite equipment to conduct this assessment. This finding is supported by (AAP, 2002), who said, health workers and facilities have the skill but lack the necessary equipment and this partly accounts for the lower detection of that the actual prevalence.

Visual and hearing impairments are major disabilities among children, and to achieve a reduction in their prevalence, demands improvements in assessments and detection rate of these defects in the various health facilities (Centre for Disease Control and Prevention, 2011). Although findings of the study indicated that many respondents possess the skill to detect visual impairment, a few of them claimed that they had the skill to detect hearing and metabolic disorders. It should be noted that visual impairments is a condition which

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can easily be identified through physical examination and other basic assessment tools. On the other hand, hearing and metabolic disorders are not easily picked through basic screening procedures because they are complex and require well equipped laboratories (Centre for Disease Control and Prevention, 2011).

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#### **5.4 Screening Schedules**

The findings indicated that there seemed to be differences in the timeframe within which screening for health problems in newborns is done. According Cole and Flexer, 2007), an important consideration for screening for early detection of potential disabilities in children is the time frame. It is vital that "abnormalities" are detected early enough so that measures can be taken to prevent permanent disabilities. The findings indicated that the time period within which screening is done for newborns is good, however, the problem is how indepth or detailed are these screening procedures to be able to pick all forms of disabilities. According to Gorham and Stout (1995), with the present technology, at least 50% of all disabilities may be prevented or postponed if screening is done early to detect developmental delay for intervention.

# 5.5 Challenges to Early Detection of Disabilities

There are myriad of challenges facing screening of infants and children for disabilities in the region making its full implementation difficult. Some of the challenges are lack of appropriate screening equipment or tools, lack of funds, inadequate skilled personnel in the various hospitals, and lack of referral centers for further management of children with disabilities. The tendency of some parents killing their babies diagnosed with disabilities was also presented as a challenge.

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The findings are in line with the assertion that lack of highly accurate screening tests, high cost and unaffordable screening tests, inequities to access screening, absence of a voluntary system of screening with informed consent, and inadequate systems of followup and support for families, are challenges to childhood screening for disabilities (Boyle

CA et al, 2005).

The resources needed to facilitate the detection of disabilities are skilled health personnel, modern technology, and screening tests. However, the findings indicated that most hospitals lacked advanced technology and equipment, and so, their ability to detect disabilities early is depended largely on skilled health personnel. It is worthy to note, however, that having skilled personnel without technology is not enough to conduct effective screening for disabilities in children. Thus providing either of this resource is not enough to increase the capacity of health facilities to screen newborn children.

A major recommendation by the participants is the need for the acquisition of modern screening equipment. Other recommendations include the provision of adequate screening tools, encouraging pregnant women to regularly attend antenatal clinics, education of mothers and parents on the signs of disabilities, training of more specialists, in-service training for health personnel on disability detection and the establishment of special well equipped screening units mandated for disability screening.

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CHAPTER SIX

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#### SUMMARY, CONCLUSION AND RECOMMENDATIONS

## 6.1 SUMMARY

It was observed that most of the respondents had a job description of a general nurse which is followed by Nursing Administrators, Doctors and then Midwives. Generally, respondents had good working experiences in the health sector, which suggests that they are likely to be knowledgeable on issues relating to screening of defects in children and infants.

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The findings indicated that screening for disabilities in newborns was generally a common practice in the health facilities across the various districts in Brong Ahafo. As part of their practice in early detecting disabilities, the respondents claimed they collected information on maternal and family obstetrical and medical history to support the process. Also, while the practice of Apgar score assessment for newborns was generally used, the usage of Brazelton as an assessment tool for newborns was not a common practice.

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It was additionally found that assessment of motor development and neurological status of newborns and children was not present in all facilities. A few facilities undertook anthropometric measurements of newborns. Most respondents strongly agreed to the assessment of newborns for signs of prematurity but few facilities actually indulge in the practice of conducting laboratory biochemical screening for hormonal disorders and screened for defects in utero.

The findings further revealed that the personnel mostly responsible for early detection of disabilities in infants and children were midwives since they spent more time with newborns and infants, although general nurses and medical doctors were also mentioned as being responsible. Most health workers had the requisite skills to detect musculoskeletal, neurological and visual impairments or defects in newborns and infants. However, it was found that detecting hearing impairment and metabolic disorders in infants and children, for example, Phenylketonuria are skills not well possessed and practiced in these hospitals.

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Moreover, the findings indicated that screening was done in most hospitals within the first hour and 48hrs after birth. The lack of skilled personnel and parental attitude were not major challenges in disability detection. Rather, lack of specialized technology/equipment, screening tools and funds were major challenges.

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Respondents recommended that there should be a well equipped unit for early detection and treatment of disabilities, provision of enough screening tools and modern equipment to every health facility and pregnant women encouraged to take antenatal care seriously.

6.2 CONCLUSION Formatted: Font color: Auto

From findings of the study it was revealed that Pediatricians and midwives and other health professionals mostly employed physical examination to conduct assessment on new born children to see if they had defections. They did this by listening to the cry of the newly born child, examining the color of the eyes, its physical appearance and skin colour. With respect to the skills of personnel responsible for early detection of disabilities, it can be concluded that many of them possessed the requisite skills to perform their duties but were

unable to utilize their skills because they lacked the necessary equipment to work with.

Thus, if personnel are well resourced, they could be in a better position to detect most defects in newborns.

The study revealed that most health facilities lacked resources such as modern screening tools or equipment which are needed for effective screening for early detection of disabilities in newborns and infants. In addition, to lack of specialized technology/equipment, unavailability of funds also posed a major challenge to the screening of children for disabilities. Early detection cannot be achieved universally without addressing the numerous problems that confront the health delivery system in the country.

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The limitation of the study includes the inability of the researcher to cover all health facilities in the region due to limited resources. A scaled up study would, therefore, be recommended in order to understand the true picture of early detection practices in the region and the country at large.

#### **6.3 RECOMMENDATIONS**

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Based on the findings of the study, the following recommendations are made: The government, Ministry of Health, Ghana Health Services, nongovernmental organisations in health, and donor agencies should see to the designing of a programme and implement strategies to ensure that all pregnant women are encouraged to take antenatal care seriously. They should be encouraged to regularly attend antenatal services. Through these visits, adequate screening can be done to detect problems that could lead to the delivery of babies with defects for prompt intervention.

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More research should be conducted in the other regions to ascertain the true picture of our health facilities' ability to facilitate early detection of disabilities in infants and children. On the back of this, the researcher calls for the establishment of a national screening programme that advocates compulsory screening for every child born in Ghana within a given time frame before discharge. This will ensure that all forms of defects, including hormonal and chromosomal ones, are detected early for intervention to prevent disabilities. As part of this programme, special units, with the requisite resources, should be created in all hospitals. For a start, this can be done on pilot basis and later scaled-up to cover the entire country.

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In addition, adequate screening tools and modern equipment should be provided to the various health facilities to facilitate the screening and early detection of impairments in infants and children. Special consideration can be given to the Maternal, Child and Reproductive Health units, paediatric units and the laboratories of every health facility.

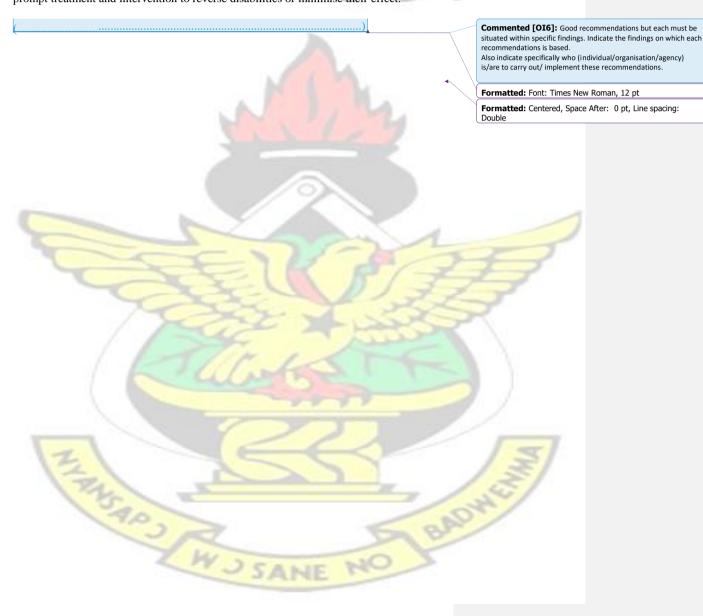
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Workshops could also be organized to create awareness on disability issues and abreast professionals with knowledge on screening for childhood defects and disabilities in children. This will sharpen the skills of the health professionals on early detection practices.

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Parents and the community are key stakeholders in the effort to reduce the prevalence of disabilities, especially among children. Parents and the communities in general should be educated on signs of disabilities in children. When equipped with this knowledge, they will be in position to detect disabilities in children and bring them to the health facilities for prompt intervention to avert complications.

Since there is the need for further management of children diagnosed with disabilities, more specialists should be train ed for this purpose. The availability of specialists would make the referral system work so that children identified with disabilities can receive prompt treatment and intervention to reverse disabilities or minimise their effect.



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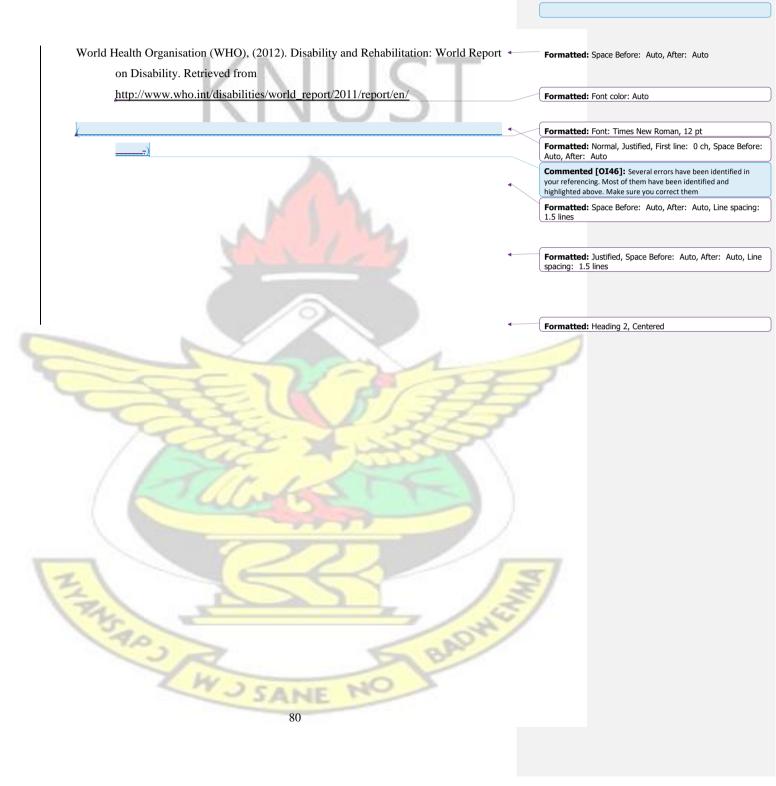
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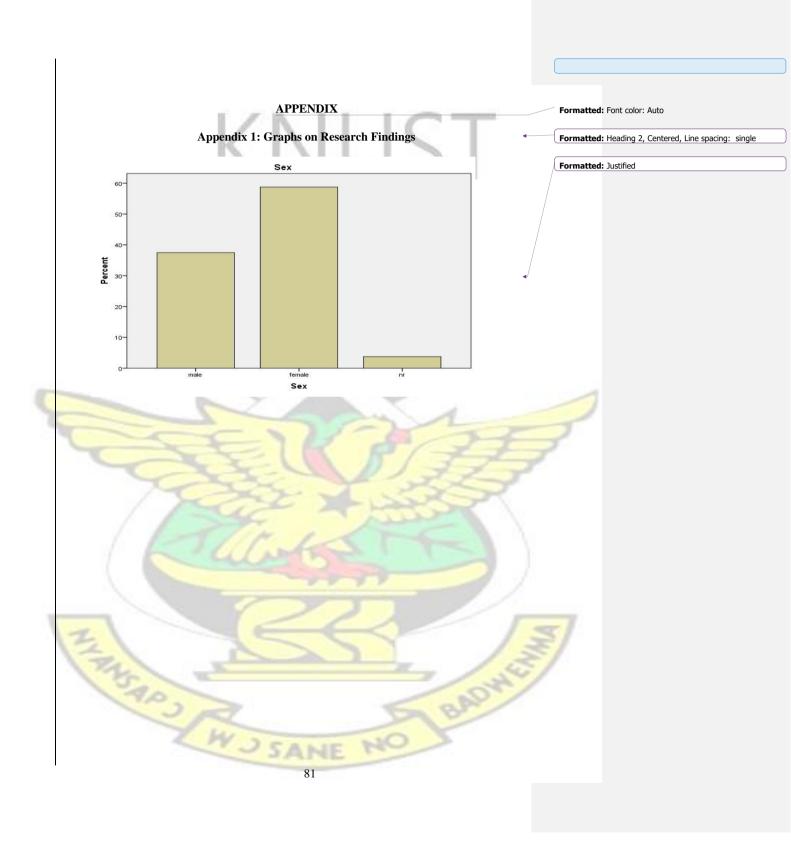
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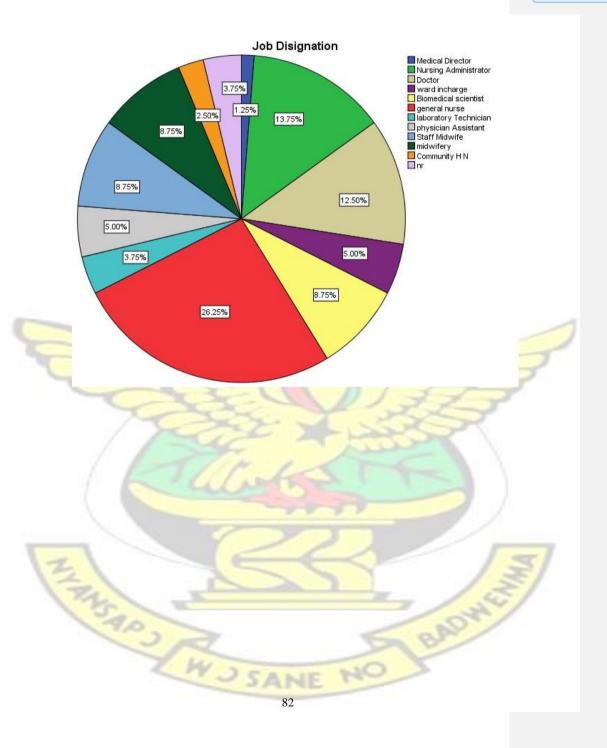
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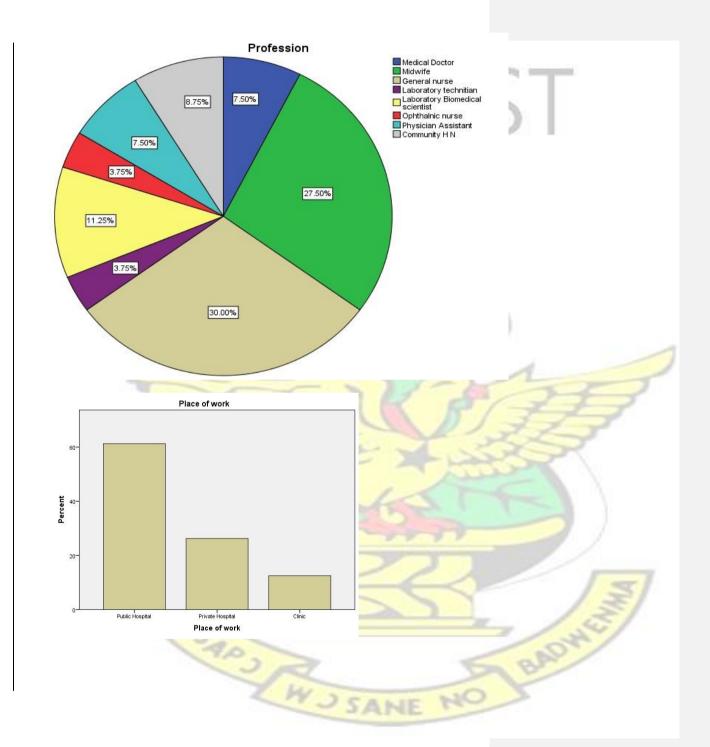
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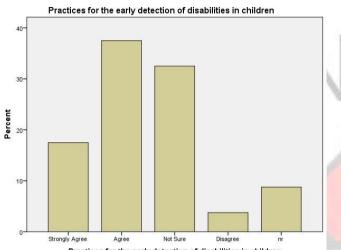
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Practices for the early detection of disabilities in children

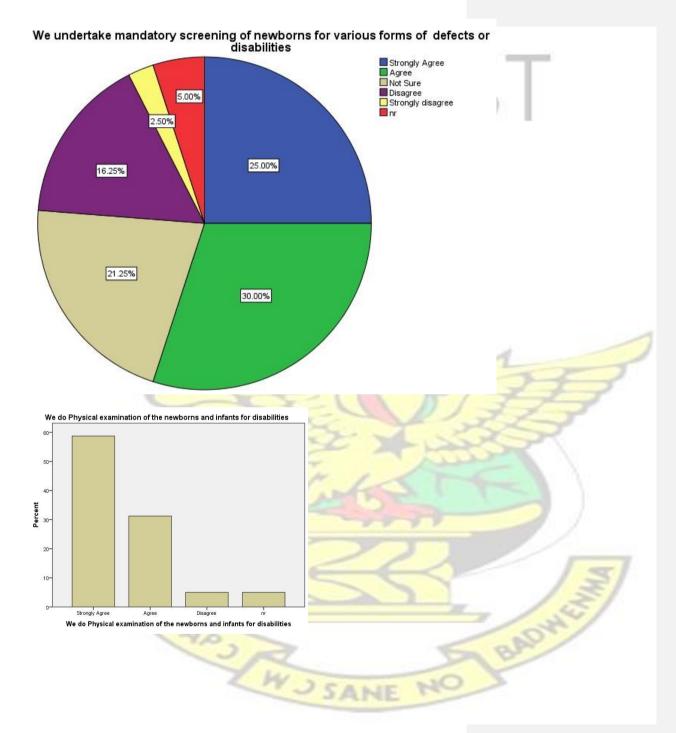


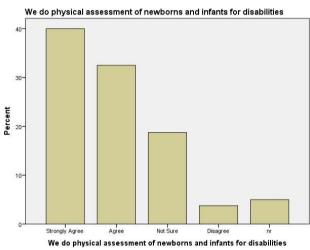
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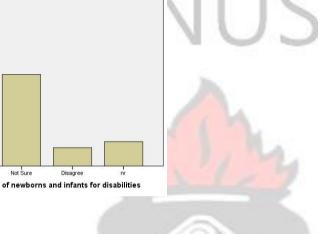
Take maternal and family's Obstetrical and medicI history of expecting mothers

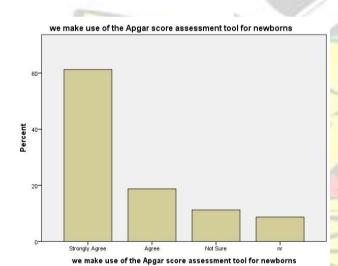
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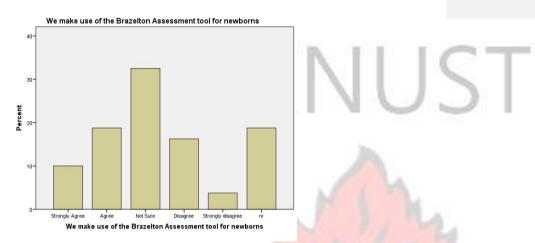
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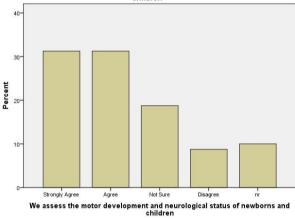


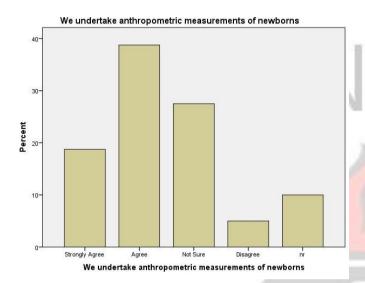


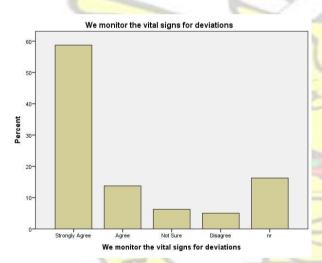


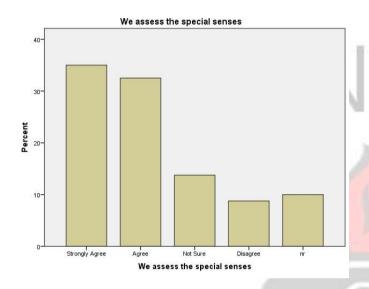


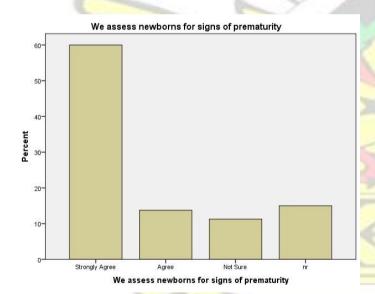
## We assess the motor development and neurological status of newborns and children

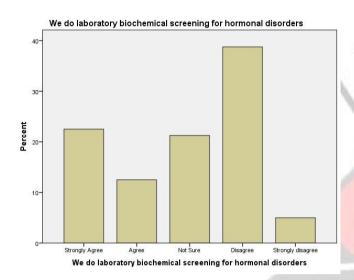


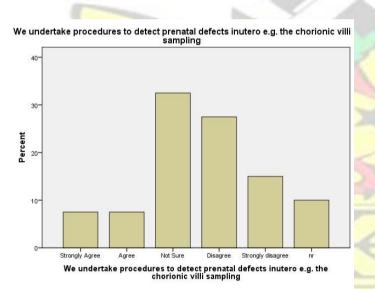


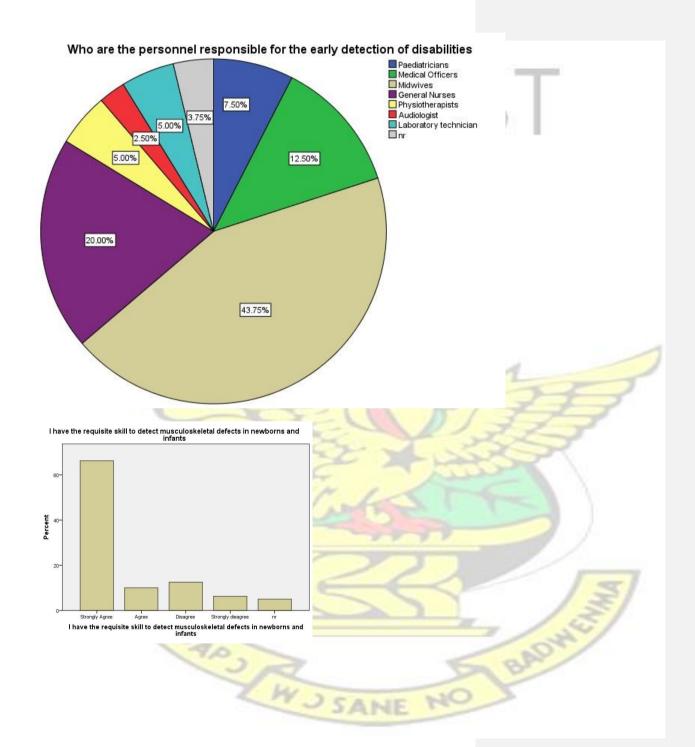


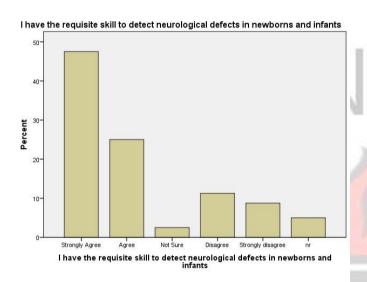


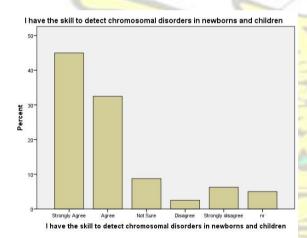


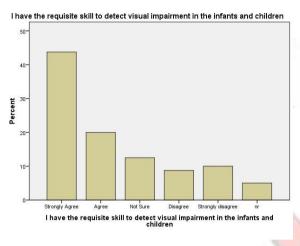




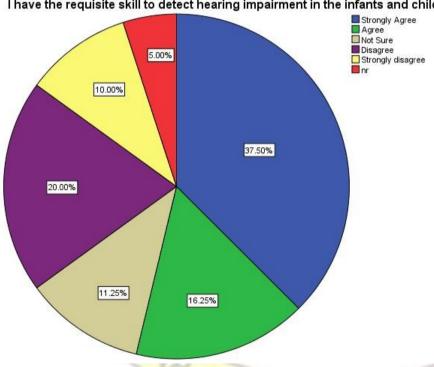




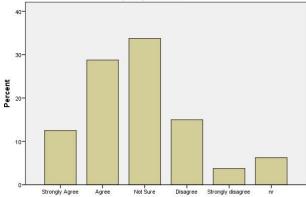




## I have the requisite skill to detect hearing impairment in the infants and children

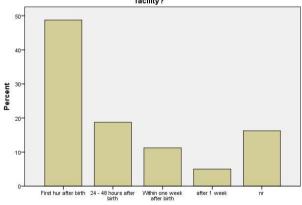




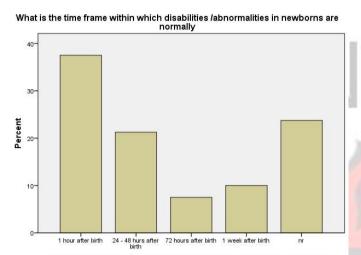


l have the requisite skill to detect metabolic disorders in infants and children e.g. phenylketonuria

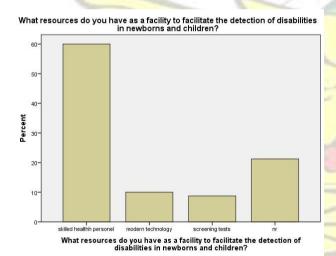
## When is screening for health problems in the newborns commenced in your facility?

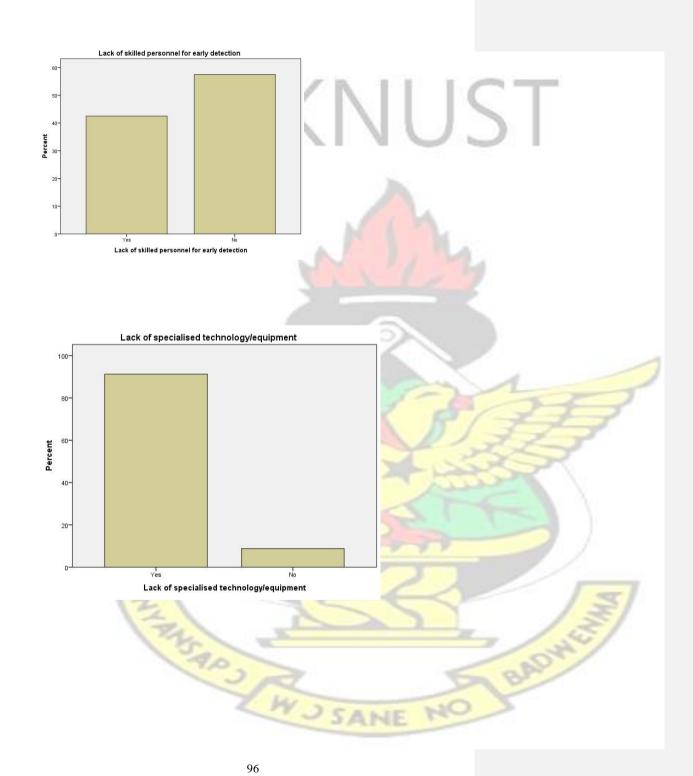


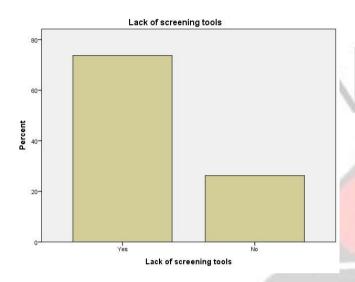
When is screening for health problems in the newborns commenced in your facility?

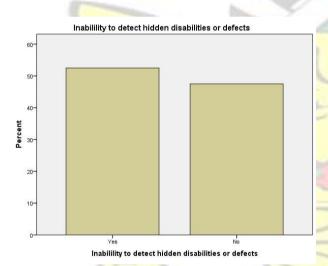


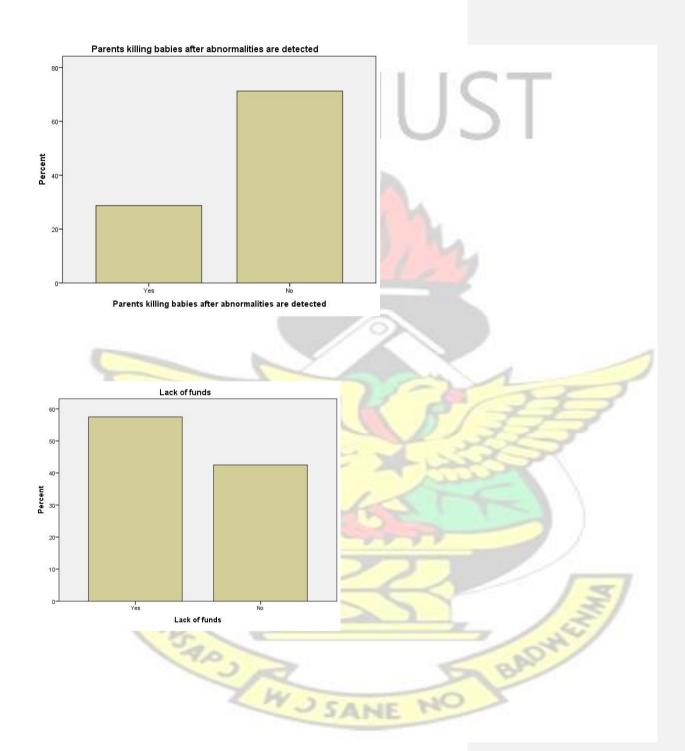
What is the time frame within which disabilities /abnormalities in newborns are normally

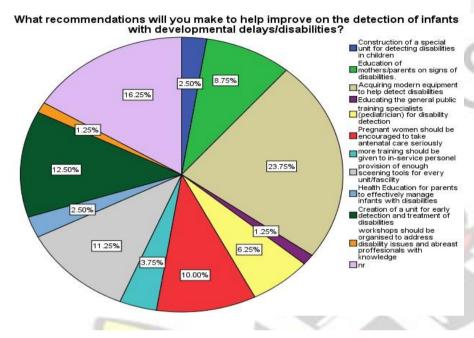


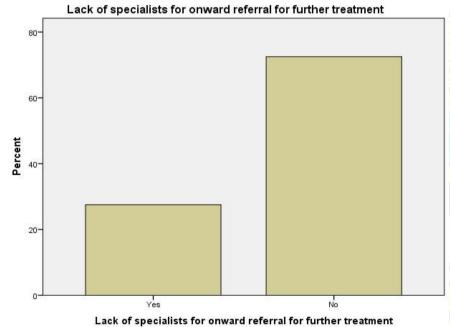












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CAME

**Introduction:** Formatted: Line spacing: Double This research is an academic exercise undertaken by Joseph Baba Yinbil a post graduate student pursuing a program in MSc Disability, Rehabilitation and Development at the Community Health Department, KNUST, Kumasi to assess the capacity of health facilities in the Brong Ahafo Region for the detection of disabilities in Children. Your Participation in this research is by your free will and completely voluntary. All information collected in this study will be coded without the names of participants recorded. Similarly no name or identity of respondents will be used in any publication or report from this study. Please you are required to complete this questionnaire and return it to the bearer by ticking in the box  $\lceil \sqrt{\rceil}$  or filling-in the spaces provided with the appropriate information. It will take about 10 -15 minutes to complete. Hitches Formatted: Justified, Line spacing: Double SECTION A: SOCIO-DEMOGRAPHICS OF RESPONDENTS Female 1. Sex: Male [ ] Formatted: Justified 2. Job designation/Specialty: Medical Director [ ] Nursing Administrator [ ] Others (specify)..... -Profession: Medical Doctor [ ] Midwife [ ] Laboratory technician [ ] 3.4. Place of work: Public Hospital [ ] private hospital [ ] Clinic [ ] Formatted: Justified

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THEDETECTION OF DISABILITIES I	N CHII	LDRE	N				
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Early Detection Practices:							
	w.,		ы.	774	2		
Respond to the following statements appropriately by ticking	ng agair	nst the	optio	n that	is		
true about the practices in your facility using the following;							
VC – very capable, C- Capable , N-Not Sure, LC-Less	s Capab	le—	_NC-	Not	4	Formatted: Justified, Indent: Left: 0", Line spacing: Double	
capable				174			
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5.6. As a facility we have practices for the early		1		P	1	Formatted: Justified	
detection of disabilities in children	_ \_			D.		Formatted: Justified	
6.7. We take maternal and family's Obstetrical and	C.		4		4	Formatted: Justified	
Medical History of expecting mothers.	2	1		1.3	50		
7.8. We undertake mandatory screening of newborns				1	4	Formatted: Justified	
for various forms of defects or disabilities			1			- A	
8.9. We do Physical examination of the newborns and	-				4	Formatted: Justified	
infants for disabilities		20					
9.10. We do physical assessment of newborns and		97		1	4	Formatted: Justified	
infants for disabilities							
10.11. We make use of the Apgar score assessment tool			-		4	Formatted: Justified	
for newborns				/			
11.12. We make use of the Brazelton Assessment tool for					4	Formatted: Justified	
newborns						1 = 1	
12.13. We assess the motor development and					4	Formatted: Justified	
neurological status of newborns and children							
13.14. We undertake anthropometric measurements of			+	-	4	Formatted: Justified	
newborns							
14.15. We monitor the vital signs for deviations	50	De 101		135		Formatted: Justified	

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15.16. We assess the special senses (i.e. assessing baby's

4.5. Work experience: Under 1 year [ ] 1 to 5 years [ ] 6 to 10 years [ ] 11

eyes for visual impairment, and ears for hearing		1	1			]
impairment)						
16.17. We assess newborns for signs of prematurity	IR.	-11	1	1	-	Formatted: Justified
17.18. We do laboratory biochemical screening for					4	Formatted: Justified
hormonal disorders	113	L.			- 3	
18.19. We undertake procedures to detect prenatal defects		V	1	J	No.	2
inutero e.g. the chorionic villi sampling						Formatted: Justified
		- 10			4	Formatted: Justified, Line spacing: Double
						, , ,
Personnel and their Skill Mix for the Early Detection of I	Disabil	ities i	n Infa	nts an	d	
Children:						
19.20. Who are the <b>personnel</b> responsible for the early determined the transfer of the early determined to the early determin	ection	of disa	abilitie	s in th	ie	
infants and children in your facility?						
Paediatricians[ ]			7			
Medical officers[ ]		Z		1		,
Midwives[ ]	1			-		1
General Nurses[ ]				3		253
Physiotherapists[]	1	0			/	377
Optometrist/ophthalmologist[ ]	2	-	1		3	
Audiologist[ ]						
Laboratory Technicians[ ]						
Others (specify)						
Z				<		/5/
121						/ = /
124					Z.,	150
100						5
W. Brand						BA
111				_		
CWS	CA		- 1	120	)	

Respond to the following statements appropriately by ticking against the option that is true about your skill in the detection of the stated disabilities in infants and children using the following;

VC – Very Capable, C-Capable, N-Not Sure, LC-Less Capable, NC-Not capable.

	ement Response -				4	Formatted: Justified, Line spacing: Multiple 1.15 li	
		VC	C	N	LC	∙NC	Formatted: Line spacing: Multiple 1.15 li
	have the requisite skill to detect musculoskeletal		1			4	Formatted: Line spacing: Multiple 1.15 li
	s in newborns and infants e.g. clubfeet,	ner/			6		
contrac	ctures, extra/incomplete digits, etc.				1		
	have the requisite skill to detect neurological					4	Formatted: Line spacing: Multiple 1.15 li
	s in newborns and infants e.g. spina bifida,					-	
•	cephalus, Erbs palsy, etc						
	ave the skill to detect chromosomal disorders in					4	Formatted: Line spacing: Multiple 1.15 li
	orns and children e.g. down syndrome		1				
	ave the requisite skill to detect visual impairment		10		140	4	Formatted: Line spacing: Multiple 1.15 li
	infants and children		1			7	
	have the requisite skill to detect hearing				1	4	Formatted: Line spacing: Multiple 1.15 li
	ment in the infants and children						
	have the requisite skill to detect metabolic				-5	1	Formatted: Line spacing: Multiple 1.15 li
disorue	ers in infants and children e.g. phenylketonuria.				H		C
						1 -	Formatted: Line spacing: Double
<del>26.</del> 27. WI							
facilit	ty?	vborns	comr	nenced	l in you	ır•	Formatted: Justified, Line spacing: Double
facilit		vborns	comr	nenced	l in you	ır•	Formatted: Justified, Line spacing: Double  Formatted: Justified
facilit a.	ty? First hour after birth	vborns	comr	nenced	l in you	ır•	
facilit a. b.	ty? First hour after birth 24- to 48-hour after birth	wborns	comi	nenced	l in you	lr∢ -	
facilit a. b. c.	rty?  First hour after birth  24- to 48-hour after birth  Within one week after birth	wborns	comi	nenced	l in you	ar∢ •	
facilit a. b. c. d.	First hour after birth  24- to 48-hour after birth  Within one week after birth  Others (specify)			2			
facilit a. b. c. d.	rty?  First hour after birth  24- to 48-hour after birth  Within one week after birth			2			
facilit  a. b. c. d.  27.28. Wh	First hour after birth  24- to 48-hour after birth  Within one week after birth  Others (specify)			2			Formatted: Justified
facilit a. b. c. d. 27.28. Wh	First hour after birth  24- to 48-hour after birth  Within one week after birth  Others (specify)	onormali	ities i	n newt			Formatted: Justified
facilit a. b. c. d. 27.28. Wh	First hour after birth  24- to 48-hour after birth  Within one week after birth  Others (specify)	onormali	ities i	n newt			Formatted: Justified  Formatted: Justified, Line spacing: Double
facilit a. b. c. d. 27.28. Wh norma a. b.	First hour after birth  24- to 48-hour after birth  Within one week after birth  Others (specify)	onormali	ities i	n newt			Formatted: Justified  Formatted: Justified, Line spacing: Double
facilit  a. b. c. d.  27.28. Wh norma  a. b. c.	First hour after birth  24- to 48-hour after birth  Within one week after birth  Others (specify)	onormali	ities i	n newt			Formatted: Justified  Formatted: Justified, Line spacing: Double

e.	Other (specify)	
· .	←	Formatted: Justified, Line spacing: Double
20 20 11	Vhat resources do you have as a facility to facilitate the detection of disabilities in	7
<del>28.</del> 29. W	vial resources do you have as a facility to facilitate the detection of disabilities in	
newb	oorns and children?	)
a.	Skilled health personnel/professionals[	1
	Formatted: Justified	
b.	Modern Technology/equipment/screening tools[ ]	
	Specify types of equipment/technology available:	
c.	Adequate funds to support screening[ ]	
d.	Screening tests[ ]	
		Formatted: Line spacing: Double
Challenge	es in the Early Detection of Disabilities in Infants and Children:	
_		Cariliania da anda dan di a
<del>29.</del> 30. w	That are the challenges faced by the facility and/or health personnel in-Formatted: Justified,	Line spacing: Double facilitating the earry detection
of dis	sabilities in newborns and children?	777
	a. Lack of skilled personnel for early detection [	7 7
	Formatted: Justified	
	b. Lack of specialised technology/equipment [ ]	
	c. Lack of screening tools [ ]	
	d. Inability to detect hidden disabilities or defects e.g. metabolic disorders []	
	e. Parents killing babies after abnormalities are detected [ ]	
	f. Lack of funds [ ]	
	g. Lack of specialists for onward referral for further treatment [ ]	
	h. Others(specify)	131
	12/	12
		22
	703	
	The state of the s	Formatted: Justified, Line spacing: Double
<del>30.</del> 31. W	That recommendations will you make to help improve on the detection of infants and	
child	ren with developmental delays/disabilities in your facility?	
	104	