Dissertation Title

Documenting Prevalence and associated risk factors for Hearing Impairment and Speech disorders among children aged 2-9 years in rural areas of district Palwal in Haryana

A dissertation submitted in partial fulfilment of the requirements for the award of

Post-Graduate Diploma in Health and Hospital Management

by

Dr. Narender Goswami

International Institute of Health Management Research
New Delhi -110075
April, 2012

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THE INCLEN TRUST INTERNATIONAL

RESEARCH AND TRAINING FOR IMPROVING
EQUITY, EFFICIENCY AND QUALITY IN HEALTH CARE

Ref: IEO Delhi/Corresp 2010/HR-INC-172

April 15th, 2012

TO WHOM IT MAY CONCERN

This is to certify that Dr. Narender Goswami as a Research Fellow has successfully completed his 3 months internship in our INCLEN Trust International from January 16, 2012 to April 15th, 2012. During this intern he has worked on Project Neurodevelopment Disabilities (NDD) in children 2-9 years, field study site Palwal, Haryana.

We wish him good luck for his future assignments.

Manoja Kumar Das

Director Projects

The INCLEN Trust International

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Certificate of Approval

The following dissertation titled "Documenting Prevalence and associated risk factors for Hearing Impairment and Speech disorders among children aged 2-9 years in rural areas of district Palwal in Haryana" is hereby approved as a certified study in management carried out and presented in a manner satisfactory to warrant its acceptance as a prerequisite for the award of Post- Graduate Diploma in Health and Hospital Management for which it has been submitted. It is understood that by this approval the undersigned do not necessarily endorse or approve any statement made, opinion expressed or conclusion drawn therein but approve the dissertation only for the purpose it is submitted.

Dissertation Examination Committee for evaluation of dissertation

Name	Signature
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DR DHARMESH GAUR	

THE INCLEN TRUST INTERNATIONAL

RESEARCH AND TRAINING FOR IMPROVING
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Certificate from Dissertation Advisory Committee

This is to certify that **Dr. Narender Goswami**, a graduate student of the **Post- Graduate Diploma in Health and Hospital Management**, has worked under our guidance and supervision. He is submitting this dissertation titled "Burden and associated risk factors for hearing and speech and language disorders among rural children aged 2-9 years in palwal, Haryana" in partial fulfilment of the requirements for the award of the **Post- Graduate Diploma in Health and Hospital Management**.

This dissertation has the requisite standard and to the best of our knowledge no part of it has been reproduced from any other dissertation, monograph, report or book.

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ABSTRACT

The neurodevelopmental disorders (NDDs) is characterized by an impairment of the growth and development either in Brain or Central Nervous System.

Neuro-developmental Disabilities (NDDs) are a diverse group of severe chronic conditions that begin at any point in development up to 22 years of age, usually lasting throughout a person's life time[(1)] and include the following specific conditions or syndromes: Intellectual Disability (ID), Autism Spectrum Disorders (ASD), Attention Deficit/Hyperactivity disorder (ADHD), Learning Disorders, Epilepsy, Hearing Impairment, Vision Impairment, Cerebral Palsy (CP), Speech and Language Disorders and Neuro-Muscular disorders (NMDs).

The most sensory deficit in human population is found out to be the loss of hearing among individuals. This presently affects more than 250 million people in the world. Consequences of hearing impairment include inability to interpret speech sounds, often producing a reduced ability to communicate, delay in language acquisition, economic and educational disadvantage, social isolation and stigmatisation

Reduced hearing acuity during infancy and early childhood not only interferes with development of speech and language skills, but also adversely affects the developing auditory nervous system. It can be harmful for social, emotional and cognitive growth, and continues to plague the individual for the rest of his/her life. Current clinical methods to identify hearing loss are convenient, cost-effective, accurate and valid and can be easily employed for early identification and intervention of hearing loss.

The potential risk factors for NDDs include biological (nutritional, genetic, infection, neurological, biochemical), environmental (abuse, socio-economic status, toxins), social (expectations, norms, peer groups) and cultural factors (ethnicity, language). In low and middle income countries, the predominant risk factors for developmental disabilities include infections, nutritional deficiencies (vitamin A, folic acid, iodine, iron and zinc) and protein-energy malnutrition, genetic factors (hemoglobinopathies contributing to stroke), drugs and environmental toxins such as lead and adverse perinatal and neonatal factors.

Neuro-developmental disabilities have always been an important concern and are considered as a significant public health problem among children especially in the low and middle income countries including India. The reason may be that attention and resources are focused to more widely prevalent and visible vaccine preventable childhood diseases, infections, nutritional deficiencies and neonatal issues.

The concept of neuro developmental disability is subjective, situational and consequently has been defined differently at various places. Thus estimates of disabled vary to a great extent depending on the definitions, the source, the methodology and the extent of use of scientific instruments on identifying and measuring the degree of disability. Although extensive data is available for individual neuro-disabilities in developed countries there is a paucity of documented data regarding comprehensive tool and its validity and reliability and prevalence of NDDs and their risk factors in developing countries like India.

In India, there exist only two official data sources, namely Census 2001 and NSSO 2002 that mentions different estimates of prevalence of disabilities. It has also been reported that there is lack of disability estimates. Currently available data from low and middle-income countries is often based on case series from referral hospitals, and as such, are not representative of the larger geographic region, or of whole spectrum of developmental disabilities and are associated with methodological problems including variable classification schemes and ascertainment strategies. Even projections from available small studies are inadequate to convince policy-makers about the magnitude of the problem. In community settings, it is necessary to distinguish between children who have the disability and those who do not. This is an important challenge both in clinical arena, where child-care is the issue, and in the public health arena, where primary and secondary prevention programs are the main focus. There is a lack of comprehensive, valid, reliable and culturally sensitive screening tool for multiple NDDs in resource constraint community settings. As the screening tools are not designed appropriately and sensitively, this leads to a huge gap between the official estimates and the alternate estimates. The situation is more worsened when it brings in the hearing and speech disability. Although enormous information is available about its prevalence and related risk factors in developed countries, there is dearth of documented data in that of the developing countries like India. Not only this, the condition even worsens when it comes to the rural parts of the country. It has been evidenced from the researches that rural areas have higher prevalence of the hearing and speech impairments as compared to that of the

scenario in urban parts. It is important to identify standard clinical diagnostic criteria that can be applied in conjunction with a screening tool and making them simplified to an extent to which locally trained professionals can respond. The system so developed has to be robust enough to collate the most acceptable and practical clinical criteria for screening of the hearing and speech disability and to identify the associated risk factors so as to strategize the effective preventive strategies. It has also been useful for efficient resource allocation and policy formulation.

The purpose of conducting this study is to highlight the problem accompanied with the hearing and speech impairments among children aged 2 – 9 years in India. It also supports the collection of information on determinants of the impairment so as to design culturally appropriate interventions thus reducing its burden in the country with efficient resource allocation and effective implementation of the preventive strategies. The primary objectives of this study is to document the prevalence of two common neuro-developmental disabilities namely, Speech and Language Disorders and Hearing Impairment among children aged 2-9 years in rural Palwal, Haryana and to explore the possible contribution of potentially modifiable risk factors like child cry, place of delivery, brain infection, head injury, etc. towards these disabilities in these children.

Key words: Neuro- developmental disorders, Hearing Impairment, Speech Disorder, Risk Factors

ACKNOWLEDGEMENT

With immense pleasure, I would like to present this project report "Documenting Prevalence and associated risk factors for Hearing Impairment and Speech disorders among children aged 2-9 years in rural areas of district Palwal in Haryana".

It has been an enriching experience for me to undergo my dissertation at INCLEN Trust International, which would not have been possible without the goodwill and support of the people around me. As a student of **IIHMR, NEW DELHI,** I would like to express my sincere thanks to all those who helped me during my dissertation.

I would like to thank Dr. N.K. Arora, Executive Director, and INCLEN Trust International for granting me the opportunity to do my dissertation at INCLEN Trust International. I would also like to thank Dr. Manoj K. Das, Director Projects, and INCLEN Trust International who was kind enough to spare his valuable time and provided several important suggestions at every stage of my study and also for guiding me towards the right path.

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However, I accept the sole responsibility for any possible error of omission and would be extremely grateful to the readers of this project report if they bring such mistakes to my notice.

Thank You

Dr. Narender Goswami

Student, PGDHHM

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ABBREVIATIONS

ADHD	Attention Deficit Hyperactivity Disorder
AIIMS	All India Institute of Medical Sciences
ASD	Autism Spectrum Disorders
CCC	Consensus Clinical Criteria
CEU	Clinical Epidemiology Unit
CP	Cerebral Palsy
FO	Field Officer
INCLEN	International Clinical Epidemiology Network
ID	Intellectual Disability
NDD	Neurodevelopmental Disabilities
NDST	Neurodevelopmental Screening Tool
NGO	Non-Government Organization
NMD	Neuro-Muscular Disorder
NMI	Neuro-Muscular Impairments
NSSO	National Sample Survey Organization
OR	Odds Ratio
OAE	Oto-acoustic Emissions
ASD	Autism Spectrum Disorder
PI	Principal Investigator
PPS	Probability Proportionate to Size
TAG	Technical Advisory Group

Part 1

Internship Report

Organization profile

INCLEN TRUST INTERNATIONAL

INCLEN (International Clinical Epidemiology Network) created in 1980 as a project of The Rockefeller Foundation registered in USA, INCLEN Inc is an independent non-profit organization since 1988. Since 1980, INCLEN has helped clinicians and other scientists obtain the knowledge and tools to improve the health of people in the developing world. Through carefully designed training and other support, INCLEN helps them critically assess the factors that determine the most effective prevention and treatment strategies.

Today their membership includes 89 clinical epidemiology units (CEUs) with a membership of 1843 members in 34 countries throughout the world. The multi-disciplinary faculty includes clinical epidemiologists, epidemiologists, health social scientists, biostatisticians, and clinical economists, each of whom believes that fighting disease in an age of limited financial resources depends on integrating the principles of clinical epidemiology into his or her practice.

> *"INCLEN is undertaking major changes… Central to these changes is the principle that an organization that is dedicated to the improvement of the health in the developing world is appropriately guided by leaders from the developing world."*

INCLEN provides a forum for researchers to discuss critical health issues through educational projects, global meetings, and an international communications network impact on health. The INCLEN Trust International envisions having global presence.

The "Original Founders" of The Trust consisted of three representatives from the Board of Directors of INCLEN Inc. (The current Chair-Dr. Claire Bombardier, Dr. Nelson Sewankambo and Dr. Marcel Tanner) and the 6 regional CLEN presidents/coordinators.

In addition to the Original Founders, it was decided to have "Associate Founders", which may be NGOs, governments or other agencies that contributed substantially to the pursuit

of the Trust's goals and objectives. This participation was deemed as important in the context of the renewed spirit of partnership and collaboration in the new Trust.

The Board of Governors, was to be the highest policy-making body of the Trust, and consisted of the CEU and CERTC directors, the regional CLEN presidents or coordinators, 3 members of the Board of Directors of INCLEN Inc., and a representative from each Associate Founder.

Mission Statement

"We are a unique global network of clinical epidemiologists, biostatisticians, health social scientists, health economists and other health professionals affiliated with key academic healthcare institutions."

"We are dedicated to improving the health of disadvantaged populations, particularly in low- and middle-income countries, by promoting equitable healthcare based on the best evidence of effectiveness and the efficient use of resources."

"We achieve this by using the network to conduct collaborative, inter-disciplinary research on high-priority health problems, and to train future generations of leaders in healthcare research."

Vision

"To attain equity in health for development through essential research and training in global health and related disciplines"

Goal

Improve the health of the populations of developing countries by promoting healthcare based on the best evidence of effectiveness and the efficient use of resources.

Objectives

1. To build and sustain research and training centres in clinical epidemiology, biostatistics, health and social sciences and related disciplines at local, national and regional levels with a view to contribute to health research programs that are responsive to local and national priorities and are linked to evidence-based health policy and action.

2. To carry out multidisciplinary collaborative research relevant to the health needs of developing countries and regions.

3. To foster networking and partnerships among national, regional, and international organizations and agencies with common goals ad activities i research and training, including development of indigenous leaders for health research policy and management.

INCLEN Inc. initially created seven semi-autonomous regional networks in Africa, India, China, Southeast Asia, Latin America, Europe-Mediterranean and Canada USA.

How INCLEN works

At the local level, INCLEN members at CEUs are trained in various disciplines through postgraduate and continuing education.

At regional level, INCLEN regional networks apply strategic approaches to health problems and training needs while linking with governments and other agencies to promote change.

At the global level, INCLEN facilitates communication; ensure access to technology, knowledge and global expertise; encourage multidisciplinary collaborative research among regions; and promotes translation of research results into active policy.

The INCLEN Trust is an international NGO registered in India and is also registered as a 501 (C) 3 not-for-profit organization in the USA. The INCLEN Executive offices in New Delhi and Philadelphia provide full service operational management for multi -centric global projects. INCLEN incorporates adherence in policies, guidelines, and regulations designed to maximize project performance while ensuring the proper local and regional networks functioning by brokering relationship between the network and international donors and by providing a channel for financial support for network sites from other agencies.

Organizational Structure

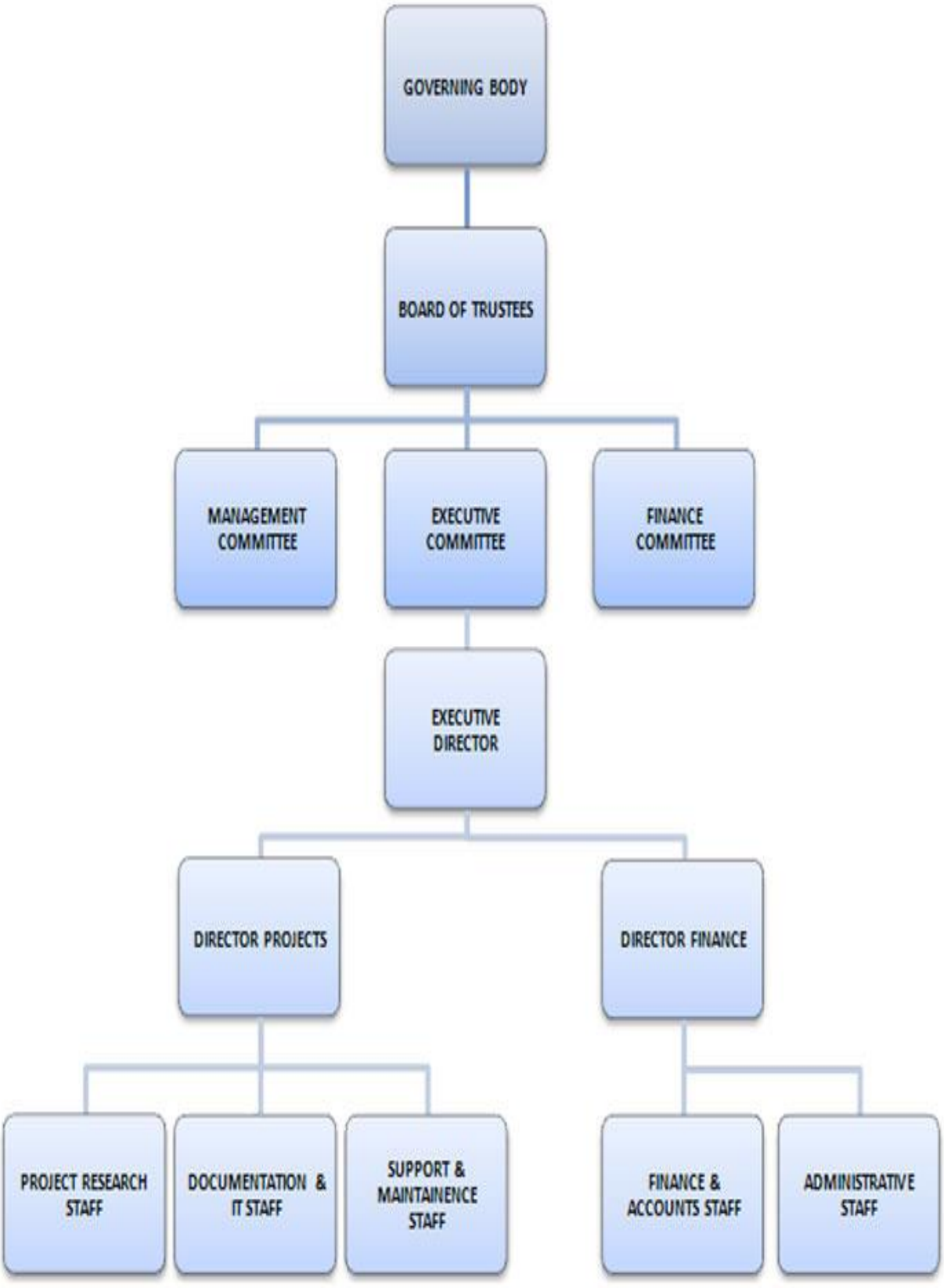
The Organization Structure below displays the formal and informal framework of policies and rules, within which INCLEN Trust has arranged its lines of authority and communications, and has allocated various rights and duties. This Organizational structure determines the manner and extent to which roles and responsibilities are delegated, controlled, and coordinated, and how information flows between the various levels of management. This structure has originated from INCLEN's objectives and the strategy chosen to achieve them.

Governance: For transparent and smooth administration of the organization, the Trust has the following administrative bodies:

i. The Governing Body

ii. The Board of Trustees

iii. Management Committee


GOVERNING BODY
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MANAGEMENT COMMITTEE
EXECUTIVE COMMITTEE
FINANCE COMMITTEE
EXECUTIVE DIRECTOR
DIRECTOR PROJECTS
DIRECTOR FINANCE
PROJECT RESEARCH STAFF
DOCUMENTATION & IT STAFF
SUPPORT & MAINTAINENCE STAFF
FINANCE & ACCOUNTS STAFF
ADMINISTRATIVE STAFF

Part 2

Dissertation Report

CHAPTER 1

Introduction

Background and Overview

Disorders of neural development fall under the categories of such disabilities. The neurodevelopmental disorders (NDDs) is characterized by an impairment of the growth and development either in Brain or Central Nervous System. A narrower use of the term refers to a disorder of brain function that affects emotion, learning ability and memory which unfolds as the individual grows.

Neuro-developmental Disabilities (NDDs) are a diverse group of severe chronic conditions that begin at any point in development up to 22 years of age, usually lasting throughout a person's life time[(1)] and include the following specific conditions or syndromes: Intellectual Disability (ID), Autism Spectrum Disorders (ASD), Attention Deficit/Hyperactivity disorder (ADHD), Learning Disorders, Epilepsy, Hearing Impairment, Vision Impairment, Cerebral Palsy (CP), Speech and Language Disorders and Neuro-Muscular disorders (NMDs). Many children have multiple disabilities and currently NDDs represent a large proportion of childhood morbidity. Antenatal period and the first few years of life (up to seven years) are the most critical period for child's development, although it is a continuous process. While severe disabilities are obviously detected early, the subtle manifestations of poor development may be observed only later during school years.

Before getting in to more of the deepened discussions about these NDDs, there is a need of clarification of thoughts on the difference between the expressions of Impairment, Disability and Handicap. However, these expressions are used interchangeably by most of the individuals but there exists a thin line of difference between the usages of these three expressions. WHO in 1980 provides a new concept of International Classification of Impairments, Disabilities and Handicaps (ICIDH) as a manual of classification which further relates with the consequences of various kinds of diseases.

Impairment is considered to occur at the level of organ or system function. Assessment of impairment requires judgment of mental and physical functioning of the body and its component parts according to accepted standards. The classification of impairment is hierarchical, allowing considerable specificity for those needing to record such detail.

The 1980 ICIDH provides a conceptual framework for disability which is described in three dimensions—Impairment, Disability and Handicap:

***Impairment**: In the context of health experience impairment is any loss or abnormality of psychological, physiological or anatomical structure or function.*

***Disability**: In the context of health experience a disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.*

***Handicap**: In the context of health experience a handicap is a disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex, and social and cultural factors) for that individual.*

Disability is concerned with functional performance or activity, and limitations therein, affecting the whole person. The disability codes attempt to encompass those activities considered important in daily life. Like impairment, the classification of disability is hierarchical but allows for an additional parameter to record the severity of disability.

Handicap focuses on the person as a social being and reflects the interaction with and adaptation to the person's surroundings. The handicap codes attempt to classify those consequences which place that individual at a disadvantage in relation to their peers. The classification system for handicap is not hierarchical, but comprises a group of 'survival roles', with each survival role having an associated scaling factor to indicate impact on the individual's life. World Health Organization (WHO) in 1980 published this International Classification of Impairments, Disabilities and Handicaps (ICIDH) to document the consequences of illness or injury. The process of impairment or injury

leading to disability and then to handicap opens up an opportunity for prevention at various levels (Primary, Secondary and Tertiary).

Whereas genetic, metabolic and birth related risk factors may be more important in the first two years of life, environmental risk factors and availability and access to community rehabilitation services may be more important beyond two years. In order to design effective strategies for prevention and to allocate resources for optimal care of children with developmental disabilities, it is imperative that we understand their nature, local prevalence, distribution, potential modifiable risk factors and utilization of available services. Once the burden is known, only then can we perform needs assessments to facilitate planning of services for children and families with special needs.

1.1

Review of Literature

Brain disorders account for over 25% of the Global Burden of Disease, and an even greater proportion in developing countries. They include some of the most devastating disorders that frequently lead to life-long disability, significant losses to the work force, and stigmatization. The scant data available leads us to believe that most or all developmental disabilities are much more prevalent in developing countries.

Global context

The most sensory deficit in human population is found out to be the loss of hearing among individuals. This presently affects more than 250 million people in the world. Consequences of hearing impairment include inability to interpret speech sounds, often producing a reduced ability to communicate, delay in language acquisition, economic and educational disadvantage, social isolation and stigmatisation[1]. The conditions gets more worsened when this impairment in childhood onset hearing loss is included as a sequel to various disease and injury causes already included in the Global Burden of Disease Study. In the Version 1 estimates for the Global Burden of Disease 2000 study, published in the World Health Report 200[2], adult-onset hearing loss was the 2nd leading cause of YLDs at global level, accounting for 4.6% of total global YLDs.

There are various definitions of hearing impairment. There are different categories of hearing impairment that ranges from "no impairment" to "profound impairment". The hearing threshold level, using audiometry, is to be taken as the better ear average for four frequencies 0.5, 1, 2, and 4 kHz. (3) The different grades of hearing impairment and their impact in performance are presented in the following Table[3].

[1] Colin Mathers, Andrew Smith, Marisol Concha. *Global burden of hearing loss in the year 2000* , 2000
[2] World Health Organization. World Health Report 2001. Mental health: New Understanding, New Hope. Geneva, World Health Organization 2001. Also available on the worldwide web at www.who.int/whr.
[3] WHO Report of the Informal Working Group On Prevention Of Deafness And Hearing Impairment Programme Planning. Geneva, 1991

Table 1 Different Grades of Hearing Impairment

Grade of Impairment	Audiometric ISO value (average of 500, 1000, 2000, 4000 Hz)	Impairment description
0 (no impairment)	25 dBHL or less (better ear)	No or very slight hearing problems. Able to hear whispers
1 (Slight impairment)	26-40 dBHL (better ear)	Able to hear and repeat words spoken in normal voice at 1 metre
2 (Moderate impairment)	41-60 dBHL (better ear)	Able to hear and repeat words using raised voice at 1 metre
3 (severe impairment)	61-80 dBHL (better ear)	Able to hear some words when shouted into better ear
4 (Profound impairment including deafness)	81 dBHL or greater (better ear)	Unable to hear and understand even a shouted voice

Source: WHO Report of an Informal Working Group, 1991

While talking about the data on prevalence and incidence rates of hearing loss in various countries, the currently available data is incomplete. Only relatively few studies have been carried out to date in representative population samples.

The global coverage of hearing aid use has been estimated to be no more than 10%, skewed towards developed countries[4]. Less than 1% of hearing impaired individuals uses hearing aids in developing countries, while in developed countries the rate ranges from 10% to 40%. Thus, the average prevalence of hearing aid use by region should be accordingly taken into account in order to calculate the average disability weight for hearing loss. Little information is available on the impact of hearing aid use on hearing disability.

Indian context

Reduced hearing acuity during infancy and early childhood not only interferes with development of speech and language skills, but also adversely affects the developing auditory nervous system. It can be harmful for social, emotional and cognitive growth, and continues to plague the individual for the rest of his/her life. Current clinical methods

[4] WHO Hearing Aids Services: Needs And Technology Assessment For Developing Countries. Report of a WHO/CBM Workshop. 24-26 November 1998.

to identify hearing loss are convenient, cost-effective, accurate and valid and can be easily employed for early identification and intervention of hearing loss[5].

In a recent survey, 4 out of every 1000 children born in India were found to have severe, to profound hearing loss[6]. It is indeed a big challenge to provide special education, vocational training and employment to this large population. There are only 540-550 special schools that cater to 3% of children with hearing impairment. There are also only 17 vocational rehabilitation centres, 22 special employment exchanges and over 40 special cells in ordinary employment exchanges, catering to their needs[7]. At present, only blue collar jobs are available to hearing impaired persons. The gravity of this problem can only be tackled if available infrastructure is used to mainstream hearing-impaired people in regular education, vocational training and employment, by attending to hearing loss on time and instituting appropriate remedial measures.

The concept of early identification and intervention though not new, is yet to gain a foothold in India. Nikam and Dharamraj attempted infant hearing screening in 1971[8]. A study[9] had been conducted in Mumbai, in 1985, a 3 year project on screening pre-school children for early identification and intervention of hearing loss. Hearing screening of neonates admitted in Neonatal Intensive Care Units (NICU) are also under way at the Wadia Children's Hospital, Mumbai and All India Institute of Medical Sciences (AIIMS), New Delhi. The effectiveness of these techniques, to identify early hearing impairment is however, questioned. Moreover, their application requires a team of specialised professionals and adequate time to record risk indicators, making the process expensive.

Professionals agree that hearing loss in infants should be recognised in time and appropriate oto-logical and audio logical rehabilitation should be instituted early, to take advantage of the plasticity of developing the sensory system (critical period is 0-3 years). This can lead to normal speech and language development, social, emotional and

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[5] M. Shamim Ansari , *Screening programme for hearing Impairment in newborns: a challenge during Rehabilitation for all,* Asia Pacific Disability Rehabilitation Journal, 2004

[6] Rehabilitation Council of India. *Status of Disability in India - 2000*. New Delhi, 2000

[7] M. Shamim Ansari , *Screening programme for hearing Impairment in newborns: a challenge during Rehabilitation for all,* Asia Pacific Disability Rehabilitation Journal, 2004

[8] Nikam S, Dharamraj. *School Screening Program in Mysore City***.** Journal of All India Institute of Speech and hearing 1971

[9] Annual Report of Ali Yavar Jung National Institute for the Hearing Handicapped (1991-92), Bandar Reclamation, Mumbai, 1992.

cognitive growth, and academic achievement in the child. In addition, identifying hearing loss before it is clinically apparent provides a baseline on which subsequent evaluation can be made and compared. Not only this, timely information also provides acceptance of hearing impairment and improves the parents' readiness to initiate a family centred rehabilitation programme. Moreover, early identification and intervention is guaranteed by the People with Disabilities Act.[10]

In a longitudinal study of 10 years, Markides[11] reported that children identified with hearing loss between 0-6 months of age with immediate audio logical and family centred programmes, have achieved significantly higher developmental function than those with delayed identification, in terms of increased expressive vocabulary and language. They have also improved syntactic comprehension / receptive vocabulary. They gained good speech intelligibility and acquired larger number of vowels and consonants.

Normal auditory integrity within the early years of life is essential for quality development of the child. Hearing loss of any degree, results in substantial and long term damages in all spheres of human life. The prevalence and incidence rate in India is quite alarming. Studies show varying prevalence rates from 1%, to as high as 40%. The Indian Council of Medical Research[12] in 1983 reported the incidence of conductive hearing loss of about 48% in rural areas. However, the National Sample Survey Organisation (NSSO) reports of 1986 showed that India had a 3.02 million deaf population, and in 1991 showed 3.24 million in the age group of 5-14 years[13]. The Human Development report of 1999, estimates a 0.3 million hearing impaired population between 0-4 years age group and 1.5 million in the age range of 5-12 years [14]. WHO in 1998, estimated 123 million people in

[10] Government of India. *Persons with Disabilities (Equal opportunities, Protection of Right and Full Participation) Act-1995.* Ministry of Law, Justice and Company Affairs; New Delhi, 1996

[11] Markides A. *The Speech of Deaf and Partially Hearing Children with Special Reference to Speech Intelligibility.* The British Journal Of Disorder Of Communication 1986

[12] ICMR. *Collaborative Study on Prevalence and Aetiology of Hearing Impairment.* Indian Council of Medical Research and Department of Science and Technology; New Delhi, 1983

[13] National Sample Survey Organisation. *A Publication of Department of Statistics,* Government of India, New Delhi. 1991

[14] Abusaleh S. *Human development Report 2000.* National Council of Applied Economic Research; New Delhi :Oxford University Press, 2000.

the world with a hearing loss of 41 dB or more, in the better ear, and a majority of them were living in Asia.

An overview of reports of developmental disabilities among children in developed and developing countries are detailed in Table 1 (A and B).

Prevalence of Developmental Disabilities

Most of the world's children live in developing countries where very little is known about the prevalence and causes of NDDs in these countries. Some forms of developmental disabilities appear to be more common in low-income countries. The table below depicts a clear picture of these differences.

Table 2 Overview of Developmental Disabilities among children in developed countries

Country/ study	Age	Conditions assessed	Prevalence and Spectrum
Metropolitan Atlanta Developmental Disabilities Study; Georgia	10 yrs of age	Developmental disabilities	ID/Mental retardation 10.3; cerebral palsy 2.0, hearing impairment 1.0; and visual impairment 0.6 per 1000 10year-old children
USA; National Health Interview Survey--Child Health Supplement	0 - 17 yrs	Developmental disabilities	Overall: 17 %; 4.9% have 2 or more Deafness or trouble hearing 3.46%; blindness 0.82%; epilepsy 0.89%; Cerebral palsy 0.23%; stammering/ stuttering 1.89%; other speech defects 2.65%; delay in growth or development 4.01%; learning disability 6.52%; emotional or behavioral problem 6.13%
USA	≥5 yrs	Disability	19 %
United Kingdom	5-15 yrs	Mental disorder	1 in 10 have a clinically

			recognizable mental disorder
United Kingdom	0-17 yrs	Disability	24 per 10,000 children received services due to a disability

Table 3 Overview of Developmental Disabilities among children in developing countries

Country/ study	Age	Conditions assessed	Prevalence and Spectrum
Israel	2- 3 yrs	76 principle medical conditions causing disability	Total disability rate of 8.9%.
India	Children 2–9 yrs	Childhood disability	Prevalence in lowest class (17.2%), two times greater than next lowest class (8.4%)
Bangladesh, Jamaica and Pakistan	Children 2–9 yrs	Childhood disability	8.2% in Bangladesh, 14.7% in Pakistan &15.2 % in Jamaica
Thiruvananthapuram, India	Up to 5 yrs	Developmental delay, deformity & disability	Developmental delay/ disability:2.50 %; Speech & Language problems (29.9%), orthopedic deformities (25.9%), Visual & hearing problem (20.2%), Cerebral palsy (12.2%), ID/Mental retardation & related (8%) and others (3.8%)
Ghana	1–15 yrs	Various cognitive, physical, sensory disabilities	Overall 18.0 / 1,000; prevalence increased with age
Northern Ethiopia	5-14 yrs	Various disability: motoric, visual, and epilepsy	Overall 4.9%, walking 1.7%, vision in one or both eyes 1.5%, hand dysfunction 0.8%, and epilepsy 0.7%

India	All age groups	Disabilities	Disabled persons = 2.129% (21.9 million) Vision: 1.034%; Speech: 0.159%; Hearing: 0.123%; Movement: 0.593%; Mental: 0.220%.
India	All age groups	Disabilities	Prevalence rate: 1.77%; 18.49 million disabled persons in 2002 (10.89 males); Loco motor disability 57.5%; blindness 10.88%; Low vision 4.39%; hearing impairment 16.55%; speech disability 11.65%; ID/mentally retarded 5.37%, mentally ill 5.95%
South Africa	2–9 year olds	Intellectual disability (ID) and associated disability	35.6/1,000 in population with ID (0.64/1,000 severe and 29.1/1,000 mild) congenital etiology 20.6%, 6.3% acquired and 73.1% undetermined. 15.5% epilepsy 8.4% cerebral palsy

The NSSO 58th round has estimated 18.49 million disabled persons in 2002, out of these 10.89 million were males and 7.59 million were females. About 57.50% disabled were having loco motor disability, while 10.88% were blind, 4.39% were having low vision, 16.55% were having hearing impairment, 11.65% had speech disability, 5.37% were mentally retarded and 5.95% were mentally ill. The prevalence rate of disability was 1.77% in 2002 against 1.88% in 1991.

Table 4 Estimation of disability in India by Census and NSSO

Estimates of Disability in India by Census and NSSO

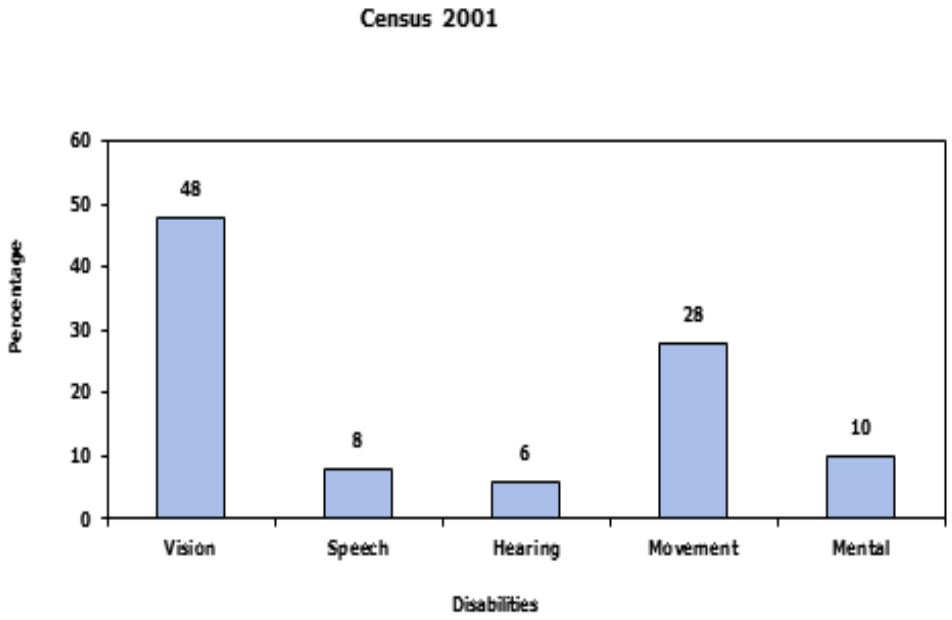
Sr. No.	Types of Disabilities	Census 2001		NSSO - 2002	
		Number	% of Total Disabled	Number	% of Total Disabled
1	Seeing	10,634,881	48.55	2,826,700	15.29
2	Speech	1,640,868	7.49	2,154,500	11.65
3	Hearing	1,261,722	5.76	3,061,700	16.56
4	Movement	6,105,477	27.87	10,634,000	57.51
4	Mental	2,263,821	10.33	2,097,500	11.34
4	Total	21,906,769	100.00	18,491,000	100.00

Source: Census of India 2001 & NSS 58th Round 2002

There are two major official sources of data on disability in India – the Census of 2001 and the National Sample Survey (NSS) Organization 58th Round, 2002. The two are not consonant with respect to the estimation of people with disabilities (PWD), with Census estimates about 18% higher than NSS estimates. Census 2001 reported 21.91 million PWD (~2.19%) while the NSS 2002 provided an estimate of 18.5 million (~1.8%). About 10.63% of the differently abled persons suffered from more than one type of disability and 8.4% and 6.1% of the total households in rural and urban India respectively have at least one differently abled person. (ICMR Bulletin, Prevention of disability in children, Vol.37, No. 4-6, June 2007) The difference in aggregate estimates is partly explainable on the basis of different definition for disabilities used in the NSS and Census.

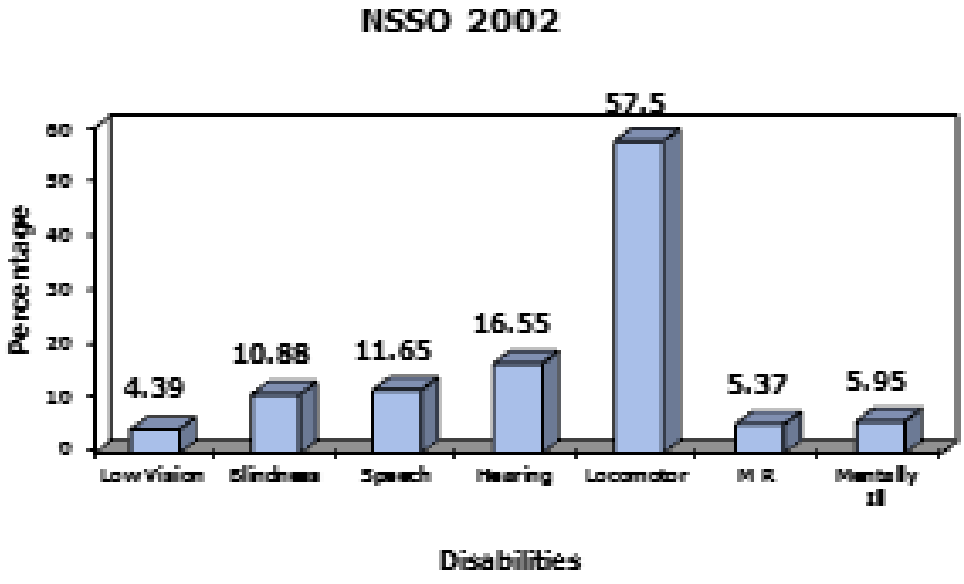
The data form the two sources can be depicted as in succeeding figures:

Figure 1 Disability in India (All age groups); census 2001



21,906,769 persons were disabled (2.1%)

Figure 2 Disability in India (All age groups); NSSO 2002



Prevalence rate: 1.77%: 18.49 million disabled persons

Potential Risk Factors for NDDs

The potential risk factors for NDDs include biological (nutritional, genetic, infection, neurological, biochemical), environmental (abuse, socio-economic status, toxins), social (expectations, norms, peer groups) and cultural factors (ethnicity, language). In low and middle income countries, the predominant risk factors for developmental disabilities include infections, nutritional deficiencies (vitamin A, folate, iodine, iron and zinc) and protein-energy malnutrition, genetic factors (hemoglobinopathies contributing to stroke), drugs and environmental toxins such as lead and adverse perinatal and neonatal factors.

Other possible risk factors include consanguineous marriages, intrauterine insult, failed abortions, and high risk mothers (younger and/or elder mothers). It has been observed that apart from obvious risk factors; poverty, lower birth weight and not receiving early stimulation have been identified as determinants of poor developmental outcome of babies at-risk for developmental delay. Maternal predictors include maternal age more than 29 years (OR=1.5); inadequate maternal nutrition (OR=1.5) and mothers who had partially immunized children (OR=2) [(14)].

The other important factors that determined the non-utilization of available services for childhood disability were identified as low education level of parents especially father, low socio-economic status of family, perceiving severity of disability as mild and poor acceptance of the interventions suggested.

Table 5 Associated Risk Factors of Developmental Disabilities

Developing countries	Developed countries
Infection* Malnutrition* Developmental problems of organic pathology** Sanitation, water supply, food hygiene, housing & education* Environmental toxins* Poverty/ unemployment* Health care* High birth rate*, consanguinity*, single mother*, attempted abortions*, younger age at marriage*; perinatal / neonatal factors*; Genetic factors	Severe, often previously fatal chronic disorders** Behavioral/ emotional disorders** Socioeconomic disadvantage among the 'have-nots'* Drug abuse, smoking, teenage pregnancies*; Genetic factors
*Modifiable risk factors	
** Some modification possible	

1.2

Rationale of the study

The concept of neuro developmental disability is subjective, situational and consequently has been defined differently at various places. Thus estimates of disabled vary to a great extent depending on the definitions, the source, the methodology and the extent of use of scientific instruments on identifying and measuring the degree of disability. Although extensive data is available for individual neuro-disabilities in developed countries there is a paucity of documented data regarding comprehensive tool and its validity and reliability and prevalence of NDDs and their risk factors in developing countries like India. It is also necessary to generate such data for efficient resource allocation and policy formulation. Information on the number and status of children with ID/mental retardation, cerebral palsy, behavioral disorders including Autism Spectrum Disorders, epilepsy, learning disorders, vision and hearing impairment and those with multiple disabilities is also needed so as to suggests the intervention afterwards.

Currently available data from low and middle-income countries is often based on case series from referral hospitals, and as such, are not representative of the larger geographic region, or of whole spectrum of developmental disabilities and are associated with methodological problems including variable classification schemes and ascertainment strategies. Even projections from available small studies are inadequate to convince policy-makers about the magnitude of the problem. In community settings, it is necessary to distinguish between children who have the disability and those who do not. This is an important challenge both in clinical arena, where child-care is the issue, and in the public health arena, where primary and secondary prevention programs are the main focus. There is a lack of comprehensive, valid, reliable and culturally sensitive screening tool for multiple NDDs in resource constraint community settings. It is equally important to identify clinical diagnostic criteria that can be applied in conjunction with screening tool in low and middle income countries by locally trained professionals. The screening system so developed has to be robust enough to collate the most acceptable and practical

clinical criteria of all NDDs and estimate the prevalence of and associated risk factors of NDD. Keeping in view the above thrusts we propose to conduct this study in two phases with overall aim of highlighting the problem of NDDs among children at the highest level and facilitating development of interventions that have the potential to reduce the burden of NDDs in India and other low and middle-income countries.

The purpose of conducting this study is to highlight the problem accompanied with the hearing and speech impairments among children aged 2 – 9 years in India. It also supports the collection of information on determinants of the impairment so as to design culturally appropriate interventions thus reducing its burden in the country with efficient resource allocation and effective implementation of the preventive strategies.

1.3

Objectives

General Objective

This cross sectional study aims

- To document the prevalence of two common neuro-developmental disabilities (NDDs)/disorders (Speech and Language Disorders and Hearing Impairment) among children aged 2-9 years in rural Palwal, Haryana:
- To explore the possible potentially modifiable risk factors responsible for these NDDs in the same population.

Specific Objectives

- To document the prevalence of speech and language disorders among rural children aged 2-9 years in Palwal district of Haryana
- To document the prevalence of hearing impairment among rural children aged 2-9 years in Palwal district of Haryana
- To document the prevalence of risk factors (social, biological, environmental, and health care) that might have predisposed the children for these two disabilities under study.

Expected Outcomes

- The prevalence of speech and language disorder in children ages 2-9 in rural area of Palwal.
- The prevalence of hearing impairments in children ages 2-9 in rural area of Palwal.
- Identification of possible contribution of potentially modifiable risk factors like child cry, place of delivery, brain infection, head injury, etc. towards these disabilities in these children.

1.4

Problem Statement

Neuro-developmental disabilities have always been an important concern and are considered as a significant public health problem among children especially in the low and middle income countries including India. The reason may be that attention and resources are focused to more widely prevalent and visible vaccine preventable childhood diseases, infections, nutritional deficiencies and neonatal issues.

In India, there exist only two official data sources, namely Census 2001 and NSSO 2002 that mentions different estimates of prevalence of disabilities. It has also been reported that there is lack of disability estimates. Also the screening tools are not designed appropriately and sensitively, thus leaving a huge gap between the official estimates and the alternate estimates. The situation is more worsened when it brings in the hearing and speech disability. Although enormous information is available about its prevalence and related risk factors in developed countries, there is dearth of documented data in that of the developing countries like India. Not only this, the condition even worsens when it comes to the rural parts of the country. It has been evidenced from the researches that rural areas have higher prevalence of the hearing and speech impairments as compared to that of the scenario in urban parts. It is important to identify standard clinical diagnostic criteria that can be applied in conjunction with a screening tool and making them simplified to an extent to which locally trained professionals can respond. The system so developed has to be robust enough to collate the most acceptable and practical clinical criteria for screening of the hearing and speech disability and to identify the associated risk factors so as to strategize the effective preventive strategies. It has also been useful for efficient resource allocation and policy formulation.

CHAPTER 2

Methodology

Context of this study

This is part of a larger study being undertaken by The INCLEN Trust International at 5 sites (Palwal, Hyderabad, Orissa, Kangra and Goa). This study is aiming to document the burden of 10 neuro-developmental disabilities and also identifying the potential risk factors for these NDDS. This data is part of the Palwal component of the study. We have included data from 5 clusters (total 50 clusters) for the Palwal study site, from Hathin Block and focused on two NDDs, Speech and Language disorder and Hearing impairment. The clusters have been identified using the PPS (Population Proportionate to Size) sampling methodology from the whole district. Hands on training have been provided by the INCLEN to research teams.

2.1

Study design

This is a cross sectional study has been employed in carrying out the assessment of the Prevalence of various neuro developmental disorders and associated risk factors. The study primarily includes Hearing and Speech Disorders in Rural areas of District Palwal in Haryana.

2.2

Study area

The data has been collected from five clusters (villages) of Hathen block of district Palwal. This area is primarily of Muslim religion.

2.3

Sampling frame

A total of five clusters (villages) have been taken. In each village 20 households were selected by random sampling.

2.4

Sampling method

Identification of the villages

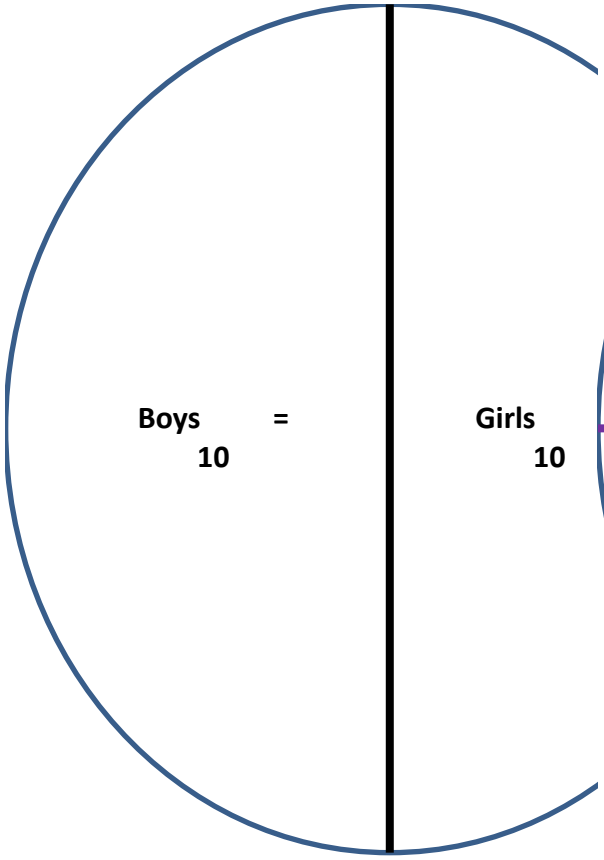
Census data (2001) (Registrar General of India) will be used for selecting clusters. For each district (study site), Census data will be arranged in three columns, with list of names of villages/administrative wards (sampling unit) in the first column, total population of that unit in the second column and cumulative population in the third column (which is obtained by adding the population of all preceding units). Sampling interval is obtained by dividing the total population in that district by the number of desired clusters (i.e. 50 clusters). A random number between one and the sampling interval is chosen as the number of the starting cluster. The unit (village or administrative ward) whose cumulative population includes this number is selected. Subsequent clusters will be obtained by adding the sampling interval to this random number until the desired numbers of the clusters are obtained. The selected clusters are plotted on a map of the respective districts and the logical sequence (route map) of the field work is developed for the survey team. The same methodology for selecting clusters will be followed in each district.

Selection of the Respondent

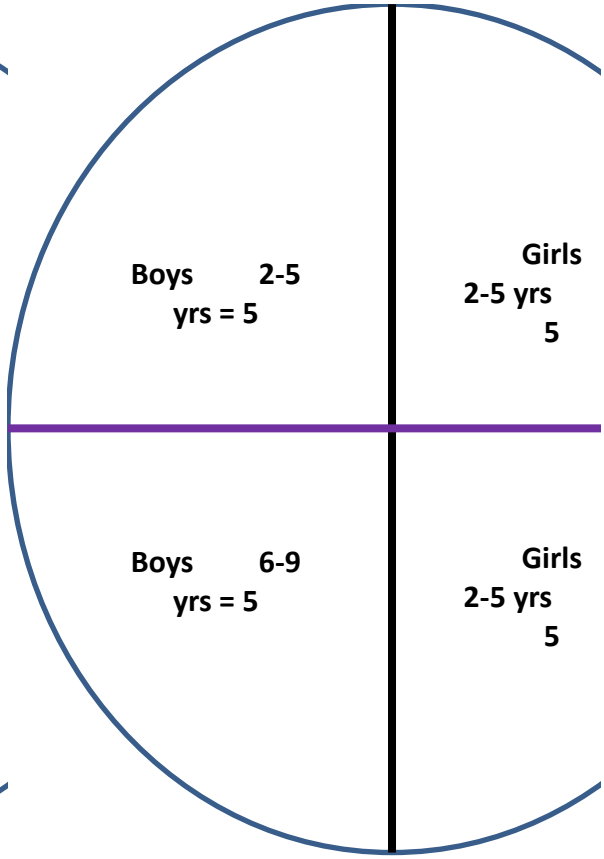
The respondent will preferably be the mother. In case mother is not available then father and if both are not available, then the primary care-taker of the child will be interviewed. If none of them are available, the team will move on to the next household. However, this household and the reason for non-selection will be recorded.

Identification of Households and Study Subjects in each cluster

Step 1: Dividing the cluster into two halves



Step 2: Dividing the cluster into 4 quarters



Selection of the starting point in a cluster

The field team will rotate an empty bottle at a central place of the cluster. In their respective halves, the research staff (Field Officer and Doctor) will select and enter the lane towards which the bottle's neck or bottom points. They will start with the first house of the lane to look for eligible children and continue moving from house to house in

consecutive lanes of that half to recruit total number of eligible children (age and sex wise).

The research staff will first look for FIVE (2 to 5) year old children of the desired sex in consecutive households. After completing five children 2 to 5 years old, they will keep on moving further to identify another FIVE 6-9 year old children of the same sex in the consecutive households. In case a household has more than one child of the desired age group and sex, then the eldest child in even numbered clusters and youngest child in odd numbered clusters will be recruited in the study.

2.5

Data collection tools and techniques

Community consent

Researchers had taken a prior verbal consent from the head of the village *(Sarpanch)* during the data collection period.

Obtaining Informed Consent

Informed consent is a process by which parent/legal guardian of the child, voluntarily expresses his/her willingness to allow his/her child to participate in the research study, after having been informed of all aspects of the research that are relevant to his/her decision. Informed consent is rooted in the ethical principle of respect for persons. It is not merely a form or a signature, but a process, involving information exchange, comprehension, voluntariness, and documentation.

Signing the consent form

If the parent/legal guardian of the child agrees to participate, the Field Study Staff will ask them to sign or give thumb impression the informed consent form. Then the consent form will also be signed by the Field Staff obtaining consent.

If the parent/ respondent is illiterate

In case the parent/legal guardian is illiterate, the Study Information Sheet will be read by the Field Study Staff in presence of a witness and the witness will then sign the consent form to document the witness procedure

Case definitions

According to Census 2011,

Speech Disorder

A person will be recorded as having speech disability, if she/he is dumb. Similarly persons whose speech is not understood by a listener of comprehension and hearing, she/he will be considered to having speech disability. This question will not be canvassed for children up to three years of age. Persons who stammer but whose speech is comprehensible will not be classified as disabled by speech.

Hearing Impairment

A person who cannot hear at all (deaf) or can hear only loud sounds will be considered as having hearing disability A person who is able to hear, using hearing-aid will not considered as disabled under this category. If a person cannot hear through one ear but her/his other ear is functioning normally, should be considered having hearing disability.

2.6

Study tool

A questionnaire was developed by Technical Advisory Group (TAG) comprising of Paediatric Neurologists, Developmental Paediatricians, Epidemiologists, Child Psychiatrists, Psychologists, Social Scientists, Ophthalmologists, and ENT specialists, Speech Therapist, Special Educators and Rehabilitation Specialists. TAG includes National as well as International experts.

Field activity

Field Team includes three members- One Doctor; Two Field Officers. The doctor and one FO (from the field team) will be involved in screening children by NDST. The children identified in field were taken to hospital for detailed assessment and confirmation by the Clinician, Audiologist, and speech therapist.

Hospital activity

Hospital Team will have **five (5) members**. One Clinician/Doctor, Three psychologists (attempt will be made to have at least one of them as clinical psychologist), one speech therapist / speech pathologist/Audiologist

Method used:

- ✓ Audiology-OAE (oto-acoustic emission)
- ✓ Speech-LPT (Linguistic profile test)

Data capturing and entry

The data for only risk factors from NDST were used in this study.
The tests and diagnosis assigned by the hospital team were used.

2.7

Data analysis

For the analysis of the questionnaire and respondent's views, SPSS Statistical Package 16.0 was used. There were several types of questions in the interview schedule, i.e. open ended questions, multiple choice questions and close ended questions. Researchers took brief notes in the field after taking their consent. Different sections were developed and analysed separately. Census 2001 and NSSO 2002 data was also referred for estimating the current scenario and practices regarding the topic of concern.

Different sections had been constructed on the basis of different risk factors. This analysis had been categorized under different sections

CHAPTER 3

Results and Findings

This chapter summarizes the results and key findings of the undertaken study. The results are interpreted in the graphical, pictorial and textual representations. The cross-tabulations have been undertaken for proceeding to the relations between the two different variables.

The results can be categorized under different sections which include:

- *Section 3.1: Profile of the respondents*
- *Section 3.2: Post natal birth infection in a child as a risk factor*
- *Section 3.3: Crying of a child immediately after the birth as a risk factor*
- *Section 3.4: Low Birth Weight of a child at the time of the birth as a risk factor*
- *Section 3.5: Medications taken by a mother during Pregnancy as a risk factor*
- *Section 3.6: Place of Delivery as a risk factor*
- *Section 3.7: Pre-mature birth of a child as a risk factor*
- *Section 3.8: Head injury in a child resulting in loss of consciousness etc. as a risk factor*

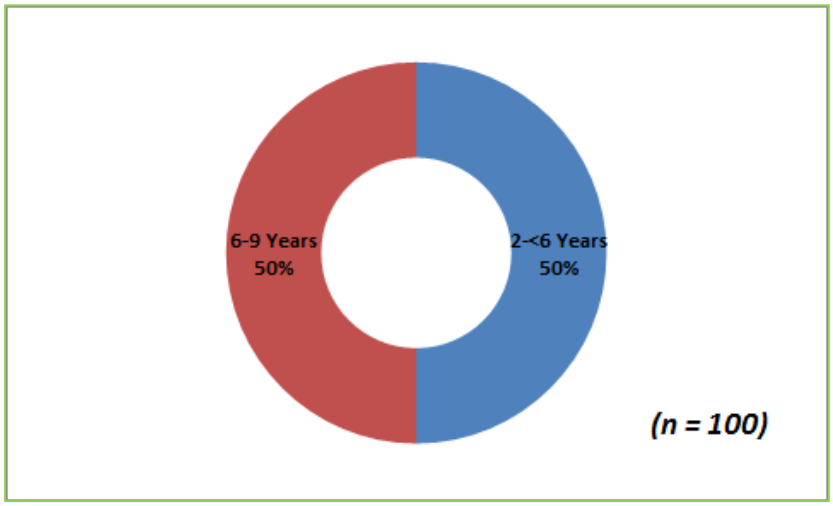
3.1

Profile of the respondents

- **Age group of the Children**

The study is being concentrated on the estimating the developmental disabilities among the children. Thus, two age groups are undertaken for the study. One age group consists of children aged between 6-9 years of age. This constitutes about 50 percent of the sample size. The other 50 percent constitute the other age group of children with 2 to 5 years.

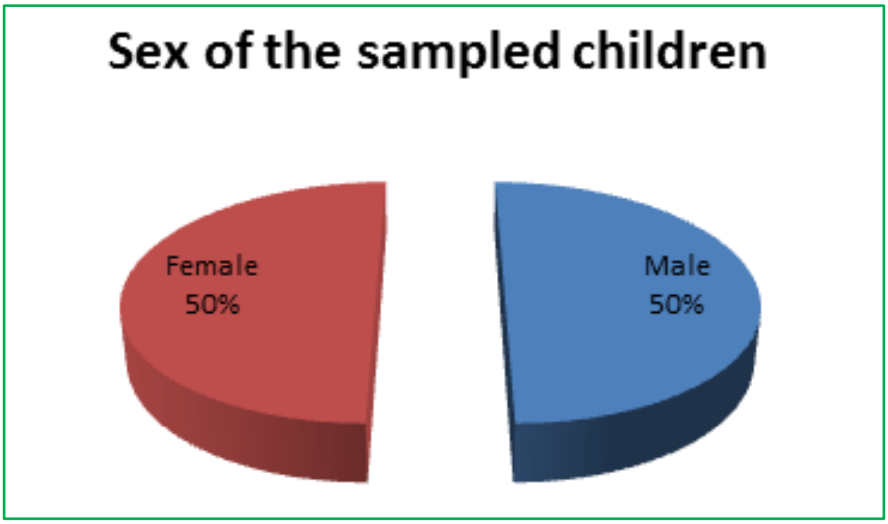
Figure 3 Age Group of the sampled Children



- **Sex of the Children**

The sex selection of the respondents has done equally with 50 percent of the girls and 50 percent of the boys as well.

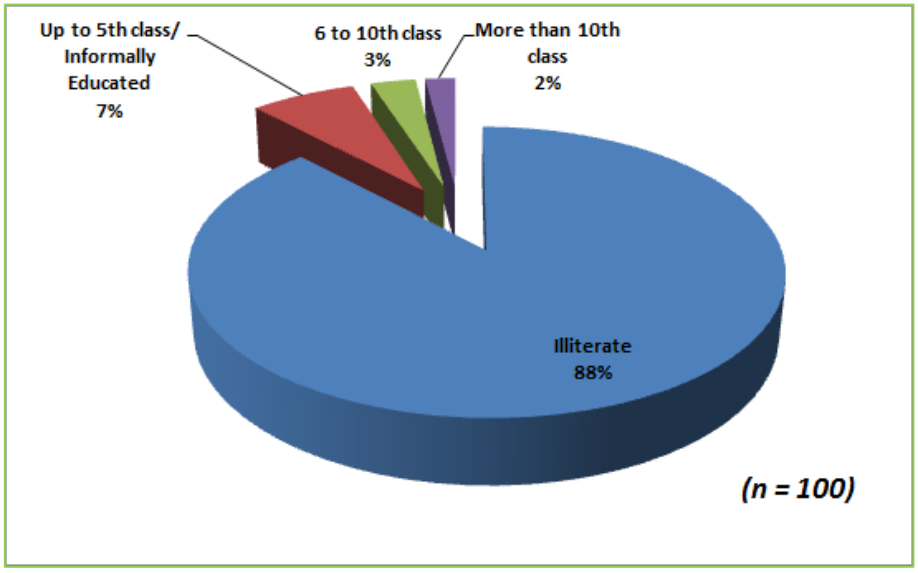
Figure 4 Sex of the sampled Children



- **Literacy levels of the respondents**

The interviews are being conducted out with the parents of the children. The educational attainment of the parents varies from village to village. This should be bring into kind consideration that almost 88 percent of the interviewee are illiterate and only 2 percent of the respondents have the educational attainment of more than 10^{th} class.

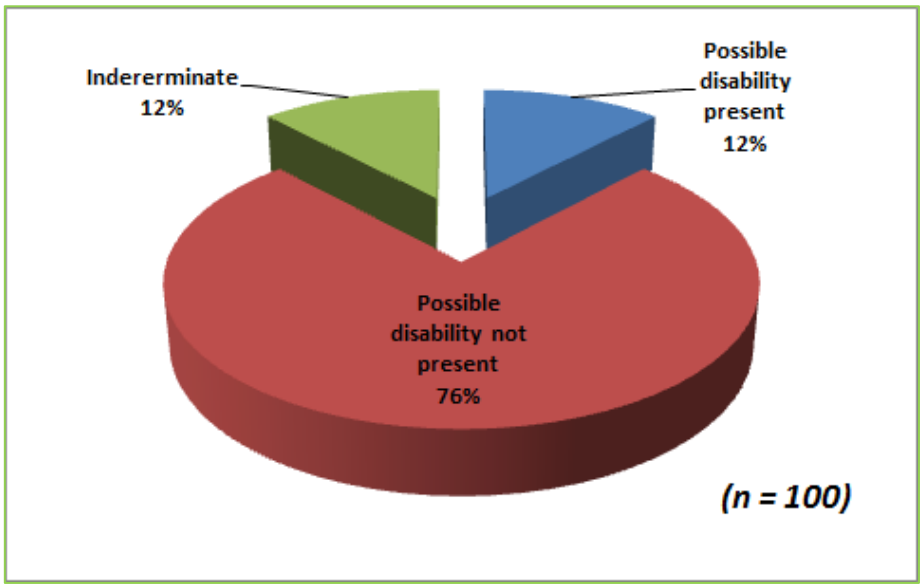
Figure 5 Literacy levels of the respondents



Possible Hearing Impairment diagnosis made by hospital team

Out of the total of 100 respondents, only 12 percent of the children have the possibility of having the disability while about 76 percent of the respondents are the ones who do not have the disability. 12 percent of the cases are indeterminate.

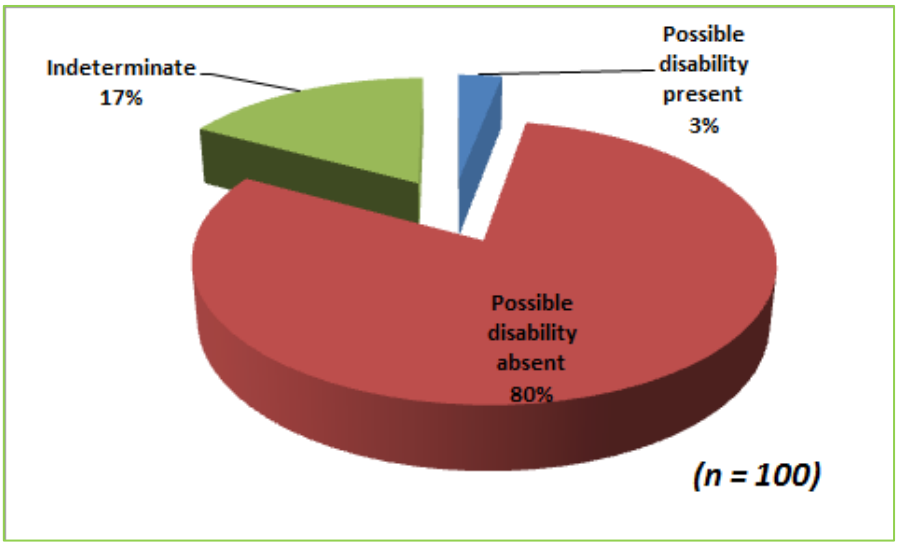
Figure 6 Total Number of children with possible Hearing Impairment



Possible Speech Disorder diagnosed by hospital team

Out of the total of 100 children, around 3 percent of the children have the possibility of suffering from one or another kind of speech disorder. Majority of the respondent do not have any sign and symptoms for the speech disorder.

Figure 7 Total Number of children with possible Speech Disorder



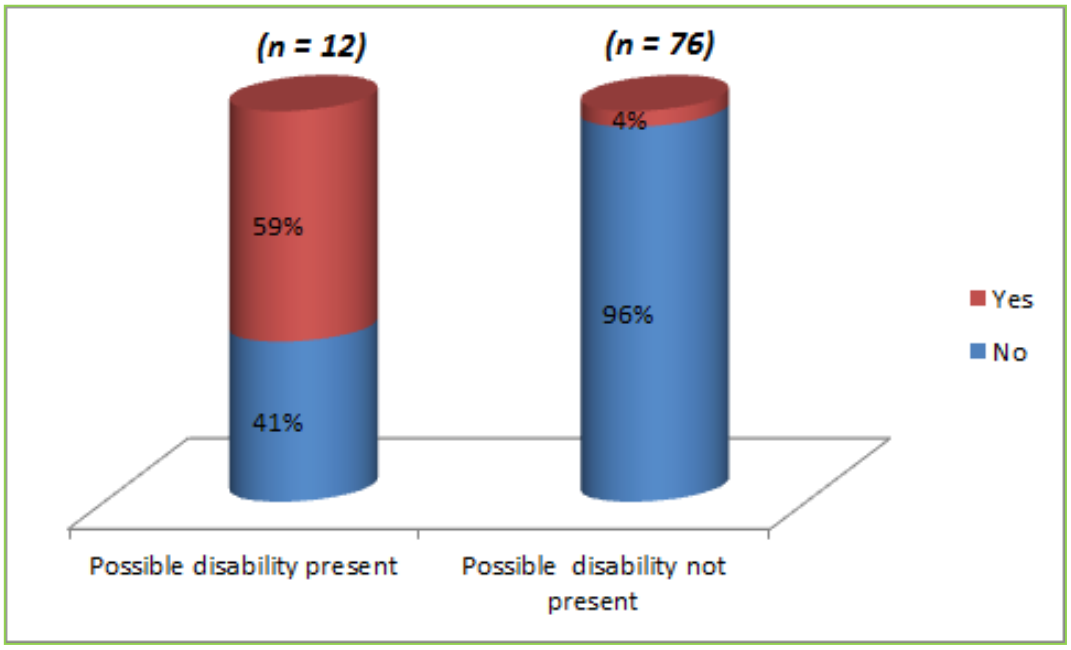
3.2

Post natal brain infection in a child as a risk factor

- **Effect on Hearing Impairment**

While 7 children among the 12 (7/12) children with hearing impairment had history of post natal brain infection, only 3 children among the 76 (3/76) without hearing impairment had the same, during which he/she had altered sensorium/loss of consciousness and/or seizures along with fever. As depicted in Figure 8, post natal infection appears to be associated with hearing impairment.

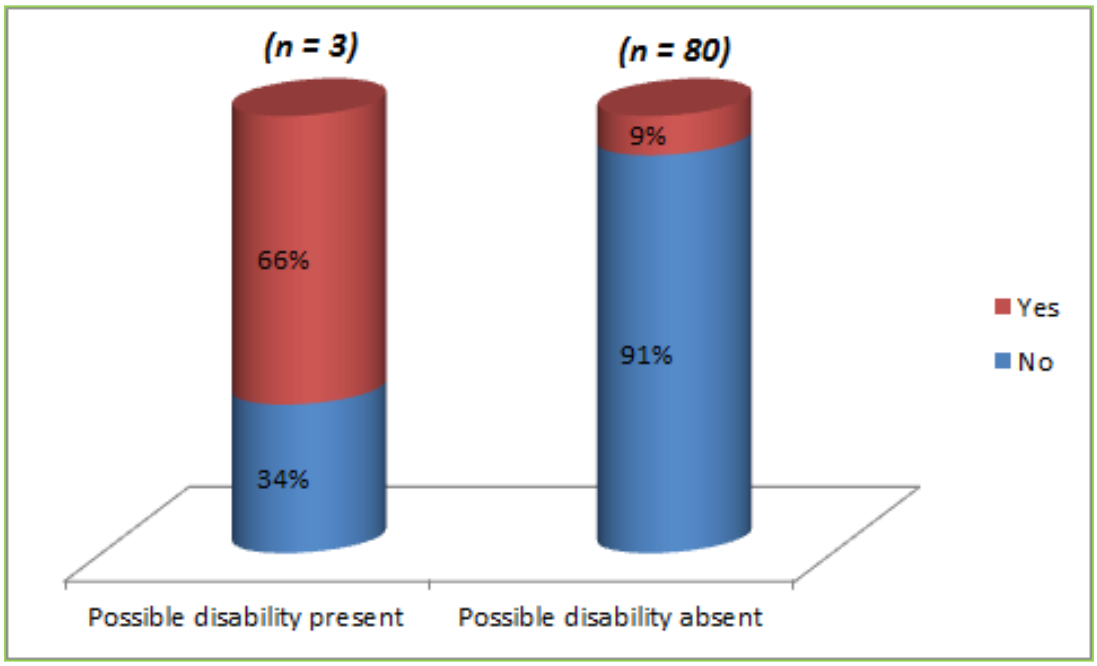
Figure 8 Relation between child with post natal brain infections (Meningitis/Encephalitis) and Hearing Impairment



Effect on Speech Disorder

Figure 9 depicts that out of three children with speech disorder two suffered with post natal brain infection during which he/she had altered sensorium/loss of consciousness and/or seizures along with fever. So it means brain infection may lead to speech disorder.

Figure 9 Relation between child with post natal brain infections (Meningitis/Encephalitis) and Speech Disorder



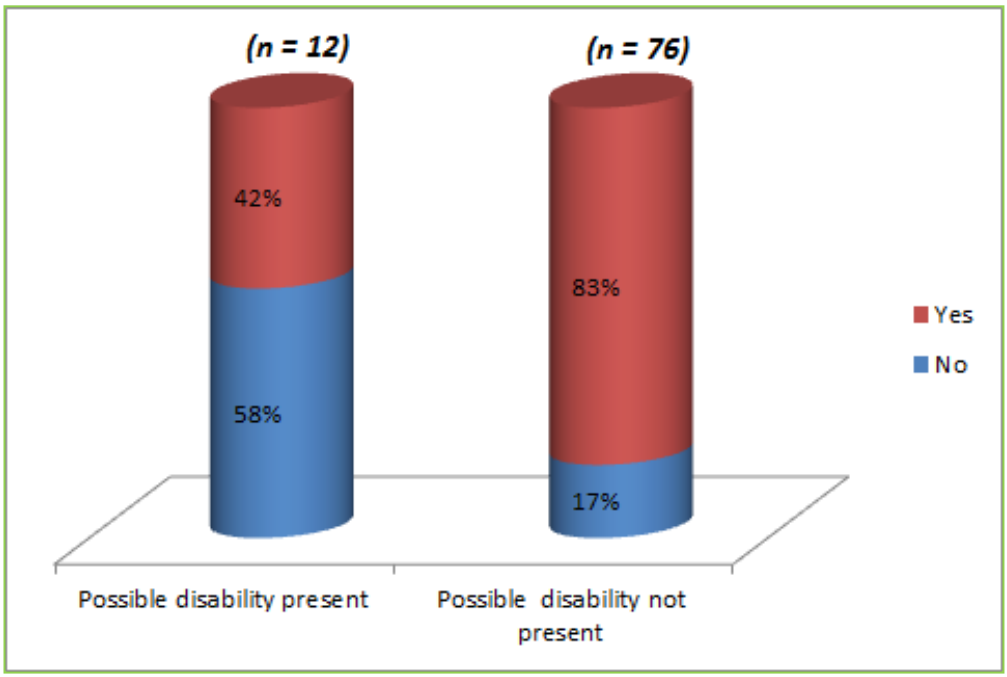
3.3

Crying of a child immediately after the birth as a risk factor

- **Effect on Hearing Impairment**

Figure 10 below depicts the Relation between child cry immediately after birth and possible Hearing Impairment diagnosed by hospital team. In this out of 12 possible hearing impaired children 7 didn't cry after birth. It means there are chances of hypoxia leads to hearing impairment.

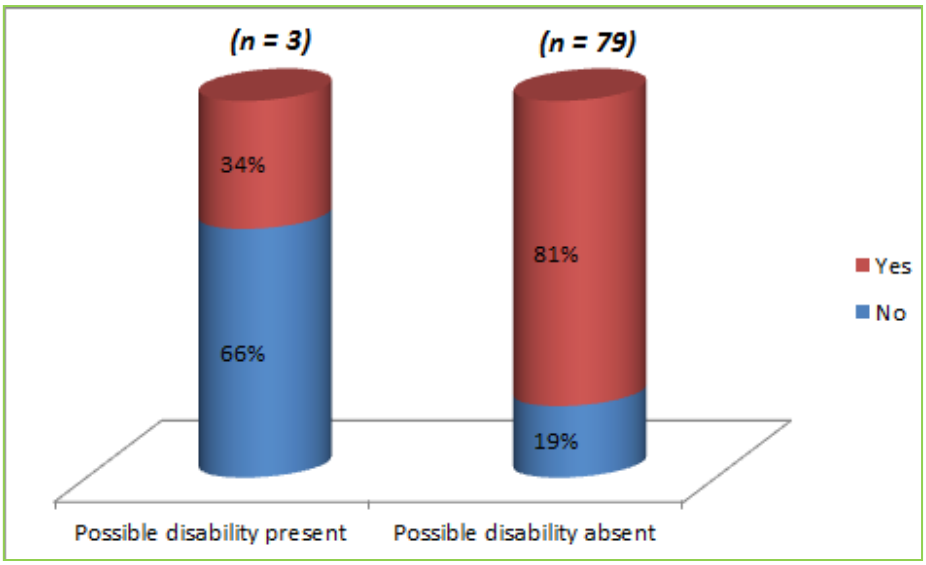
Figure 10 Crying of a child immediately after birth as a risk factor for Hearing Impairment



Effect on Speech Disorder

Among the three cases of possibly speech impaired children represented in the following data, only one child didn't cry after birth is found to be suffering from speech impairment. Whereas in the other two cases it could not be ascertained from the mothers whether their child cried at the time of birth or not. It indicates the unawareness on the part of the parents of the children to understand or notice the importance of child cry soon after the delivery**.** This can be illustrated by the following Figure 11.

Figure 11 Crying of a child immediately after birth as a risk factor for Speech disorder Impairment



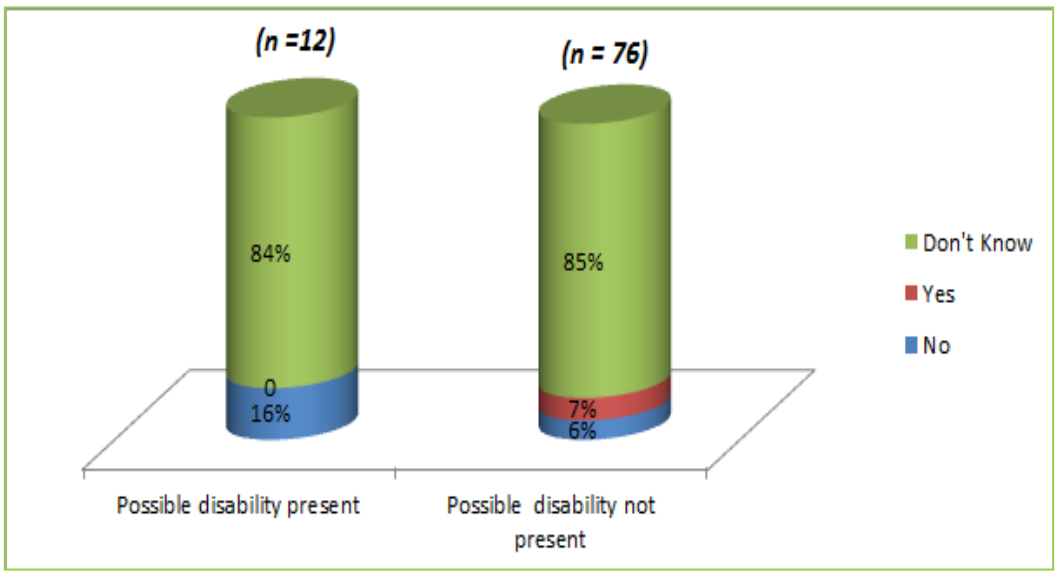
3.4

Low Birth Weight of a child at the time of the birth as a risk factor

- **Effect on Hearing Impairment**

Figure 12 shows that out of a total of twelve possible hearing impaired child, only two were found to have low birth weight and IUGR at the time of birth whereas in rest of the ten cases, it could not be ascertained from the mother whether their child was born with low birth weight or not. So it is learnt that mothers themselves were not aware of the actual weight of their children after birth.

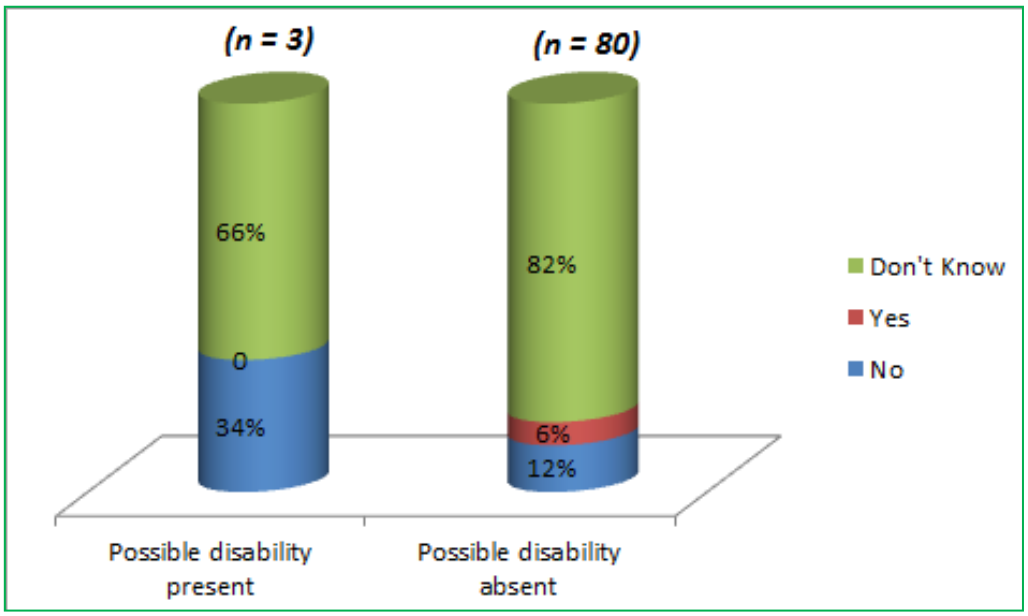
Figure 12 Effect of Low birth weight (weighing less than 2.5 Kg at the time of birth), Intra uterine growth restriction on possible hearing impairment



Effect on Speech Disorder

The mother who gave birth to children with hearing impairment was under any kind of medication during their gestation period which has more or less caused speech impairment in the children they bore. Effect of low birth weight of a child at the time of his/her birth on the speech disorder of the child can be demonstrated as in below Figure 13.

Figure 13 Effect of Low birth weight (weighing less than 2.5 Kg at the time of birth), Intra uterine growth restriction on possible Speech impairment.



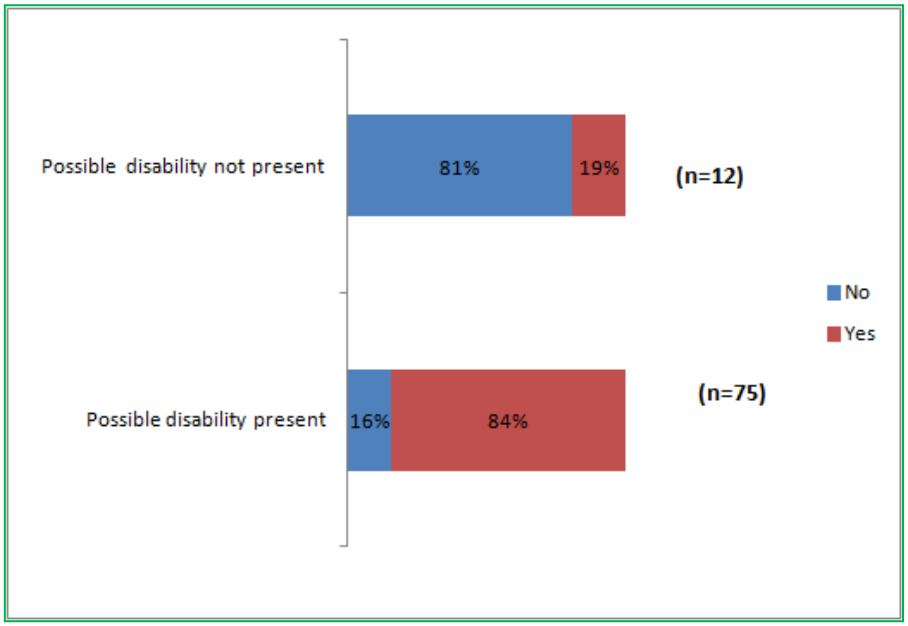
3.5

Medications taken by a mother during Pregnancy as a risk factor

In this out of 12 possible hearing impaired children 10 were delivered by mothers who had taken medication during pregnancy other than Iron, Folic acid and Calcium supplements. So we can infer that medication (other than Iron, Folic acid and Calcium supplements) during pregnancy has a direct impact on hearing of child.

- **Effect on Hearing Impairment**

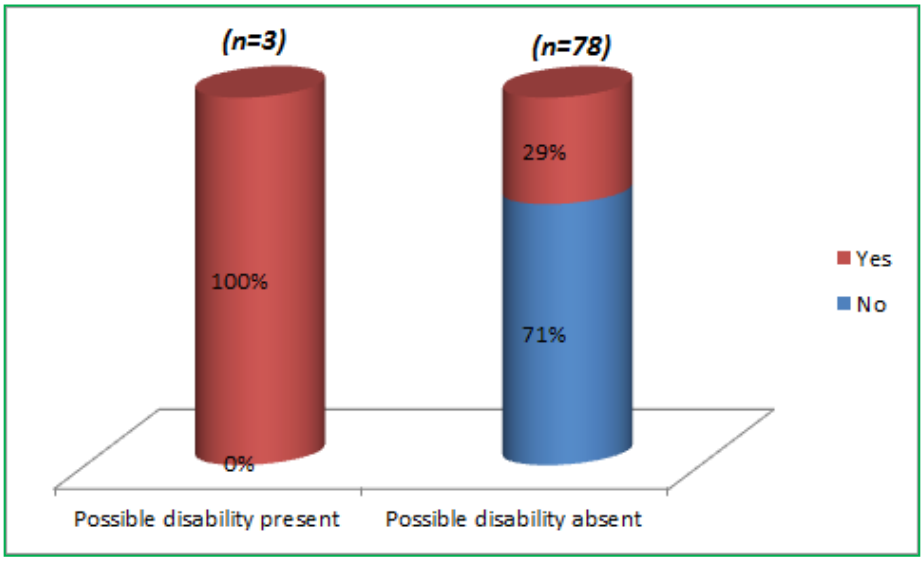
Figure 14 Impact of medications taken by child's mother (other than Iron, Folic acid and Calcium supplements) during pregnancy on Hearing Impairment



Effect on speech

In the Figure 15, all the three children who suffered from speech disorder were borne by the mothers who have taken any medications other than Iron, Folic acid and Calcium supplements during pregnancy. So it implies that certain medication during pregnancy may lead to Teratogen effect on foetus during gestation period leading to speech disorder.

Figure 15 Impact of medications taken by child's mother (other than Iron, Folic acid and Calcium supplements) during pregnancy on Speech Disorders



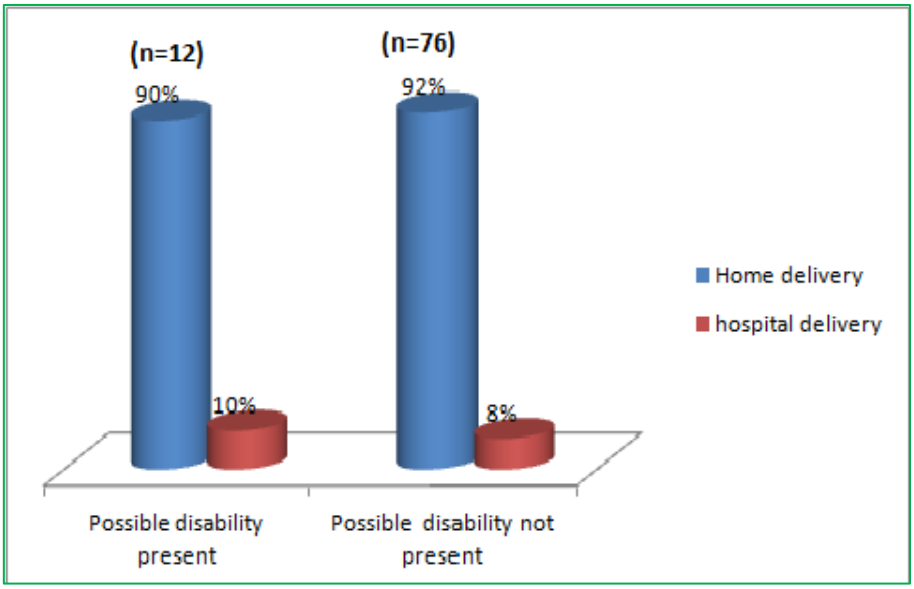
3.6

Place of Delivery as a risk factor

- **Effect on Hearing Impairment**

In Figure 16 below, it has been depicted that among the total of 12 children, 10 were found to be born at home (7 deliveries were helped by trained attendant and rest three were unattended home deliveries) and only one was at hospital. It can be inferred from the data that absence of trained attendant may lead to certain circumstances that causes various impairments among the new born. It thus implies that deliveries at hospital amidst all requisite facilities should be encouraged.

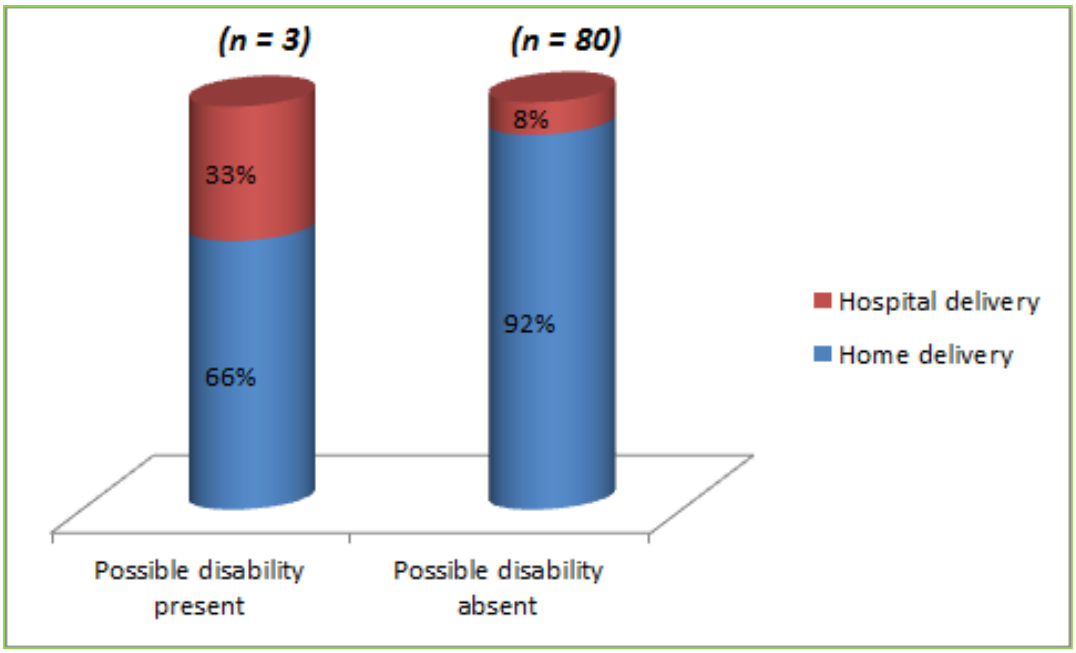
Figure 16 Place of delivery as a risk factor for possible Hearing Impairment in a child



Effect on Speech Disorders

It is a known fact that unattended deliveries may be a reason of several disorders among the new born therefore it should be promoted that more and more deliveries take place at hospital. This can be illustrated through the following Figure 17.

Figure 17 Place of delivery as a risk factor for possible Speech Disorder in a child



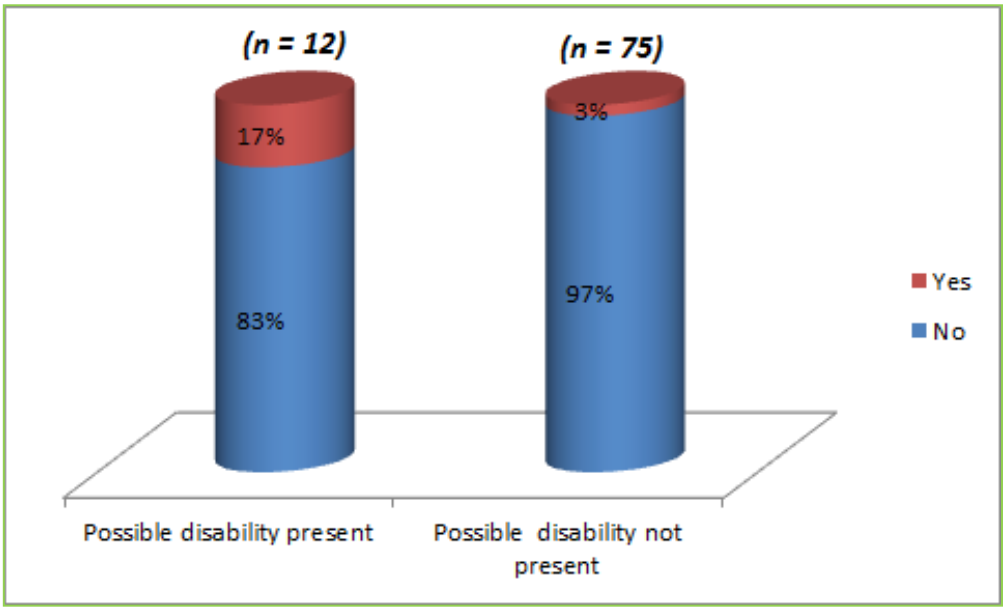
3.7

Pre-mature birth of a child as a risk factor

- **Effect on Hearing Impairment**

A no. of children who took birth even after completing nine months of gestation have been found to be suffering from hearing impairment in this 83% premature birth leads to hearing Impairment whereas 17% were from full term delivery. Figure 18 shows a clear picture of effect of pre-mature birth of a child on the disability of the children.

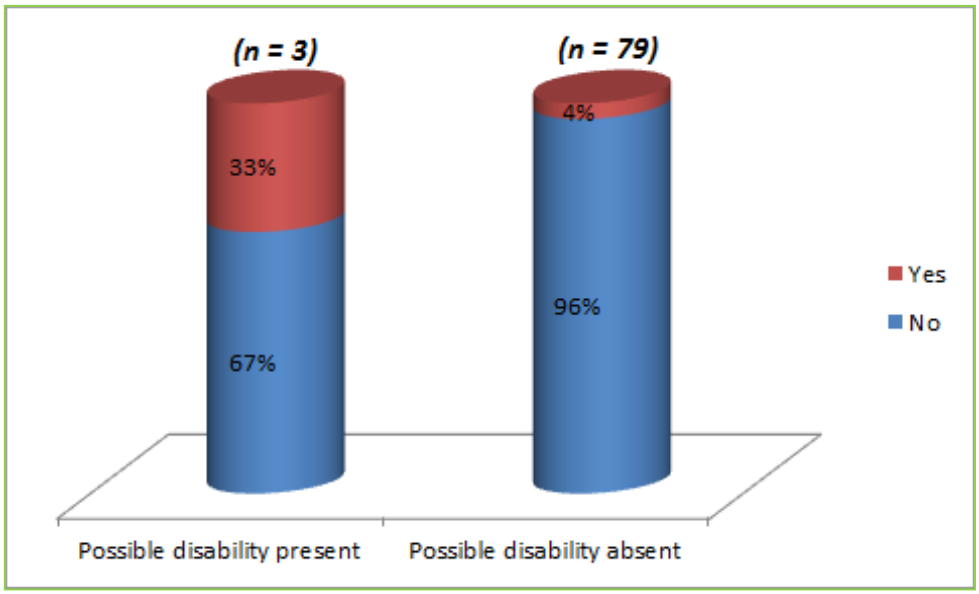
Figure 18 Relation between Pre-mature birth of child and Hearing Impairment



Effect on Speech Disorder

It is shown in Figure 19 that speech impairment was found even in two normal birth cases which implies that it is not necessary that only prematurity leads to speech impairments.

Figure 19 Relation between Pre-mature birth of child and Speech Disorder



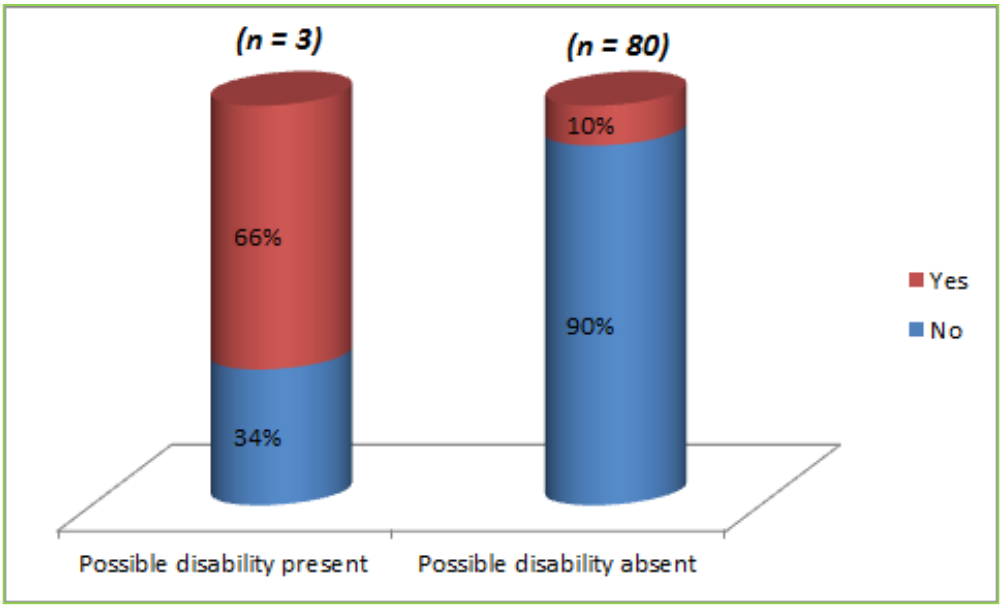
3.8

Head injury in a child resulting in loss of consciousness etc. as a risk factor

- **Effect on Speech Disorder**

Out of three children who suffered head injury, two were found with speech disorder. It is shown in Figure 20 that an injury to head may lead to speech disorder.

Figure 20 Effect of head injury resulting in loss of consciousness, repeated vomiting with/without seizures on Speech Disorder



CHAPTER 4

Discussion

This research study is an attempt to estimate the prevalence of the Hearing Impairment and the Speech Disorder among the children from the age group of the 2 to 9 years of age. This study focuses on gauging various risk factors that contributes to the disabilities of Hearing impairment and Speech Disorder, particularly in rural areas.

The previous chapter highlighted the findings of the research study as per the objectives of the study, as mentioned in the first chapter. It showed the findings in the form of tables and graphical illustrations. The data was also interpreted and discussed on the basis of their implications.

The purpose of this chapter is to discuss the findings obtained while analysing each section of the previous chapter. The findings thus obtained will then be portrayed in the light of the theory given in the first chapter. The chapter looks at the significant trends within the findings and draws up the general conclusions.

4.1

Discussion

The various risk factors assessed throughout the study embraces the following:

Post natal brain infections in a child, head injury in a child, low birth weight of the child at the time of the birth, crying of the child after the birth, etc. each one has been classified separately under the different heads.

Post natal brain infection in a child

Infection is a risk factor for adverse neurodevelopmental outcome in preterm new-borns. Infected new-borns had brain imaging measures indicative of delayed brain development. This leads to hearing impairment as it has been observed from the findings that out of the total children with the hearing impairment, around 60 percent of the child has been infected with the post natal brain infection.

These findings suggest that postnatal infection is an important risk factor for widespread abnormalities in hearing.

Interventions likely to have the greatest impact on preventing cognitive disabilities among children in the country include expansion of existing iodine supplementation, maternal literacy, and poverty alleviation programs as well as prevention of intracranial infections and their consequences. Further population-based studies are needed to confirm and understand the association between consanguinity and serious cognitive disability. Also in the less developed countries where risk factors for childhood disabilities are prevalent and the age structures of populations are weighted toward the young, the need for public health initiatives to prevent these disabilities is especially pronounced. Effective prevention, however, requires better information on risk factors and causes than is currently available for populations in the less developed world.

Child Cry immediately after the birth

The cry of the child just after his/her birth also acts as an indicator of the hearing impairment in the child. A child usually cries so as to show the responsiveness to the outer environment. If there is some delay in crying of the child or if he does not cry at all, then it can act as one of the most important indicator of hearing and the speech disorder. This can be concluded from the above findings that out of the 12 cases that have the possibility of hearing impairment, majority of the children did not cry after their birth.
Similar is the case with that of the children who are suffering form the speech disorder. Out of the 3 children who are suffering from the speech disorder, around 66 percent of the children did not cry after birth. Also in the case of the children who are not suffering from the speech disorder, only 19 percent of the children did not cry after their birth.

Low birth weight of a child at the time of the birth

If a child, just after his/her birth, weighs less than 2.5 kg, then the child is considered as the child with low birth weight. It also depicts a clear picture of possibility of Intra-uterine growth rate. During the study, it has been observed that being illiterate, most of the mothers are not aware about the birth of their child at the time of the birth. Most of the cases have answered option 'Don't know' in response to the question. Around 84 percent of the respondents constitute this group. Thus, the results are not being derived from the cases. Literature suggests that there is a relation between the low birth weight of the child at the time of the birth and hearing and speech disorders among the children. It can be concluded that the mother who gave birth to children with hearing impairment or with speech disorder were undergone medications during their gestation period which has more or less caused speech impairment in the children they bore.

Medication taken by the mother during pregnancy

Medications taken by the mother during her pregnancy has lot of positive as well as negative effect on the birth of the child. During the various ANC visits to the hospital, a mother has to undergone various medicines for the benefit of the new born. These medications general include normal drug supplements such as iron tablets, folic acid

tablets and calcium supplements. But, if mother had taken a different set of medications then that will have adverse effects on the birth of the child. It can lead to various neuro developmental disabilities, especially on hearing and speech disorder. It can be observed from the findings that out of 12 possible hearing impaired children 10 were delivered by mothers who had taken medication during pregnancy other than Iron, Folic acid and Calcium supplements. So we can infer that medication (other than Iron, Folic acid and Calcium supplements) during pregnancy has a direct impact on hearing of child. Also, all the three children who suffered from speech disorder were borne by the mothers who have taken any medications other than Iron, Folic acid and Calcium supplements during pregnancy. So it implies that certain medication during pregnancy may lead to Teratogen effect on foetus during gestation period leading to speech disorder.

Place of delivery of the child

Most of the deliveries in the rural areas take place in home itself. This also indicates that mothers are not given proper ANC treatments during her pregnancy. This can also lead to disability in the children. The findings inferred from the above cases shows that place of delivery also contribute to hearing impairment in the child because it has been depicted that among the total of 12 children, majority of the deliveries takes place at home. Similar is the case with the speech disorder in the child. Majority of the children who are suffering from speech disorder, almost 70 percent of deliveries have been taken place in the homes, while only 30 percent of the cases had been delivered in the hospitals.

Pre- mature birth of the children

Pre- mature delivery of the children leads to many developmental disabilities in the children. Not only developmental disabilities, but they can also lead to several other kinds of physical and mental disabilities. Also, a no. of children who took birth even after completing nine months of gestation have been found to be suffering from hearing impairment in this 83% premature birth leads to hearing Impairment whereas 17% were from full term delivery. similarly, in the case of the speech disorder , it is found out that even in two normal birth cases which implies that it is not necessary that only prematurity leads to speech impairments.

Head injury in the children

Head injuries during the time of the birth can lead to loss of consciousness, repeated vomiting with or without seizures which further leads to hearing impairment and speech disorder. It can be inferred from the findings that head injury also acts as a risk factor for the hearing impairment and speech disorder. Out of three children who suffered head injury, two were found with speech disorder. It is shown in Figure 18 that an injury to head may lead to speech disorder.

4.2

Limitations of the study

- The small sample size is one of the major constraints in the study. The sample size is 100 children in total. Even then, enough of the parameters had been taken into account during the study.

- The time constraint of around 3 months is another limitation for the study.

CHAPTER 5

Conclusions and Recommendations

In this study, a lot of risk factors were identified which contribute to hearing impairment and speech and language disorder.

5.1

Conclusions

The following conclusions are being derived from the study:

- The area which was selected is a Muslim dominated area and there is a huge lack of health awareness. Among these people 88% were illiterate.

- Among all 3% were Hearing impaired and 12% were of speech and language disorder. 34% children were found to have history of head injury resulting in loss of consciousness, repeated vomiting with/without seizures and they were found to have Speech Disorder so head injuries should be avoided. In case of pre mature birth 67 % child with this history were having Speech Disorder while in case of hearing impairment 83% were premature.

- Place of delivery has a huge impact on hearing and speech disorders. in case of hearing impairment it has been found that among the total of 12 children, 10 were found to be born at home (7 deliveries were helped by trained attendant and

rest three were unattended home deliveries) and only one was at hospital. It can be inferred from the data that absence of trained attendant may lead to certain circumstances that causes various impairments among the new born. It thus implies that deliveries at hospital amidst all requisite facilities should be encouraged. In case of speech disorder 66% were those children who were delivered at home. So it shows clearly the importance of hospital deliveries.

- Impact of medications taken by child's mother (other than Iron, Folic acid and Calcium supplements) during pregnancy has direct affect on mother's health and subsequently on the child's health.

- In this study all speech and language disorder children were borne by mothers who had history of medication (other than Iron, Folic acid and Calcium supplements) during pregnancy. The precise name of the medicine was not identified due to lack of awareness of mothers.

- Low birth weight also acts as one of the risk factor. During the study, it has been observed that being illiterate, most of the mothers are not aware about the birth of their child at the time of the birth. Most of the cases have answered option 'Don't know' in response to the question. Around 84 percent of the respondents constitute this group.

- Child's cry after birth is a major risk factor for Hearing impairment and speech disorder. A child usually cries so as to show the responsiveness to the outer environment. If there is some delay in crying of the child or if he does not cry at all, then it can act as one of the most important indicator of hearing and the speech disorder. This can be concluded from the above findings that out of the 12 cases that have the possibility of hearing impairment, majority of the children did not cry after their birth. Similar is the case with that of the children who are suffering from the speech disorder. Out of the 3 children who are suffering from the speech disorder, around 66 percent of the children did not cry after birth.

5.2

Recommendations

- All infants should have access to hearing screening using a physiologic measure before 1 month of age.

- All infants who do not pass the initial hearing screen and the subsequent rescreening should have appropriate audio logic and medical evaluations to confirm the presence of hearing loss before 3 months of age.

- All infants with confirmed permanent hearing loss should receive intervention services before 6 months of age. A simplified, single point of entry into an intervention system appropriate to children with hearing loss is optimal.

- The system should be family centred with infant and family rights and privacy guaranteed through informed choice, shared decision making, and parental consent.

- An effective link between health and education professionals is needed to ensure successful transition and to determine outcomes of children with hearing loss for planning and establishing public health policy.

- Families should have access to information about all intervention and treatment options and counselling regarding hearing and speech loss.

- The child and family should have immediate access to high-quality technology, including hearing aids, cochlear implants, and other assistive devices when appropriate.

- All infants and children should be regularly monitored.

- Continued assessment of communication development should be provided by appropriate providers to all children with or without any risk factors for hearing and speech loss.

- Appropriate interdisciplinary intervention programs for children suffering from the losses and their families should be counselled regularly. Intervention programs should recognize and build on strengths, informed choices, traditions, and cultural beliefs of the families.

- Information systems should be designed to interface with electronic health records and should be used to measure outcomes and report the effectiveness of the existing services at the community and state level.

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APPENDICES

APPENDIX 1

Glossary

GLOSSARY

Consensus Clinical Criteria: The criteria for diagnosis of Neuro-developmental disabilities in children are based on the best currently available evidence and / or consensus among the National and International experts, using minimal investigations, to be used in resource constrained settings.

Disability: *D*efined as "any restriction or lack of ability to perform an activity in the manner or within the range considered normal for a human being" according to WHO.

Handicap: It is defined as "a disadvantage for a given individual, resulting from impairment or a disability that limits or prevents the fulfillment of a role that is normal (depending on age, sex and social and cultural factors) for that individual" according to WHO**.** Total or partial decrease in the ability to detect or understand sound. However, for the purpose of current study, "Hearing Impairment" is defined as "Unaided hearing threshold for the better ear of 35 dB or greater"

Impairment: According to WHO, "any loss or abnormality of psychological, physiological or anatomical structure or function", e. g., Mental Retardation, Defective Vision, etc.

Neuro-developmental Disabilities (NDDs): These are a diverse group of severe chronic conditions (ADHD, ASD, CP, Epilepsy, Hearing Impairments, Learning Disorders, ID/Mental Retardation, Neuro-muscular Disorders, Speech and language Disorders and Vision Impairments) that begin at any point in development up to 22 years of age, usually lasting throughout a person's life time.

Prevalence: Prevalence means all current cases (old and new) existing at a given point in time, or over a period of time in a given population.

Reliability: It is the degree of stability exhibited when a measurement is repeated under identical conditions. It refers to the degree to which the results obtained by a research instrument can be replicated.

Risk Factors: An attribute or exposure that is significantly associated with the development of disease.

Sensitivity: the ability of a test to identify correctly all those who have the disease.

Specificity: the ability of a test to identify correctly those who do not have the disease.

Validity: expresses the ability of a test to separate or distinguish those who have the disease from those who do not.

APPENDIX 2

Study Tool

Study Tool

Risk Factors

45b. Were the child's parents related to each other (i.e. blood relation) before marriage? No Yes (mention the relationship……) 9. Do not know/ Not sure	
46b. Does any of your family member/relative have or ever had neurological or mental illness like mental subnormality, epilepsy etc? 0. No 1. Yes (Specify the illness……) 9. Do not know/ Not sure	
47b. Did any of child's mother's pregnancies result in abortion or still birth or death of child immediately after birth? (History of pregnancy losses) 0. No 1.Yes, (Specify_____) 9. Do not know/ Not sure	
48b. Did the child's mother have any of the following problems during the pregnancy? 0.- No 1.- Yes 9.- Do not know/ Not sure 48b.1.Fever with skin rash (Intrauterine infections) especially during first 3 months 48b.2.Vaginal bleeding along with pain (Abruptio placentae) 48b.3.Symptoms of high blood pressure, like headache, excessive	

weight gain, and edema (Preeclampsia) 48b.4. Diabetes Mellitus	
49b. Did the child's mother receive any medications other than Iron, Folic acid and Calcium supplements during pregnancy? 0. No 1. Yes (Specify the medications…….) 9. Do not know/Not sure	
50b. Did the child's mother have exposure to radiation like X-ray, Computerized tomographic (CT scan) scan during pregnancy? 0. No 1. Yes (Specify the gestation at which exposed_____weeks) 9. Do not know/Not sure	
51b. Did the child's mother have any exposure to pesticides e.g. DDT, endosulfan, malathion, deltamethrin, propoxur (baygon) at home, workplace and / or in the fields during pregnancy? 0. No 1. Yes (Specify the gestation at which exposed……..weeks) 9. Do not know / Not sure	
52b. Did the child's mother have fever just before/during/immediately after birth of this child? (Chorioamnionitis) 0. No 1. Yes 9. Do not know/Not sure	
53b. What is the birth order of the "index child". 0. First	

1. Second 2. Third or more 9. Do not know/Not sure	
54b. Was it a single birth? 0. No (Specify whether twins/triplets/quadruplets _____) 1. Yes 9. Do not know/ Not sure	
55b. Was your child born prematurely i.e. before completing 9 months gestation? 0. No 1. Yes (Specify how much premature: Delivered at _____week of gestations) 9. Do not know/ Not sure	
56b. Where was the child born? Home delivery attended by trained birth attendant (Dai) 1. Unattended home delivery 2. Hospital delivery 9. Do not know/Not sure	
57b. Was your child delivered by emergency caesarean section, instrumental delivery (forceps, ventouse) or breech presentation? (Emergency caesarean section and instrumental delivery) 0. No 1. Yes 9. Do not know/ Not sure	

58b. Did your child cry immediately after birth?

0. No

1. Yes

9. Do not know/ Not sure

If the child cried immediately after birth, skip the questions 59b and 60b.

59b and 60b

59b. Did the birth attendant have to do anything to the baby to make him/her cry?

0. No

1. Yes

9. Do not know/ Not sure

If the answer is “No”, skip the question 60b and go to 61b 60b

60b. Did the child have “excessive cry”/”seizures”/”inability to suck” during the first 3 days after birth?

0. No

1. Yes

9. Do not know/ Not sure

JOIN AFTER SKIP to 61b

61b. Was your child looking very small or weighing less than 2.5 Kg at the time of birth? (Low birth weight and Intra uterine growth restriction) 0. No 1. Yes (Specify the birth weight_____) 9. Do not know/ Not sure	
62b. Did your child have any of the following difficulties during first month after birth? 0. No 1. Yes (Specify the reason if known_____) 9. Do not know/ Not sure 62b.1 Brain infection or pneumonia (Fever, breathing difficulty with chest retractions) requiring hospitalization 62b.2 Deep jaundice with yellow palms and soles or jaundice requiring hospitalization and phototherapy/exchange transfusion 62b.3 Severe illness with altered sensorium or loss of consciousness with/without seizures requiring hospitalization 62b.4 Tetanus	
63b. Did your child ever have head injury due to which he/she had loss of consciousness, repeated vomiting with/without seizures? (Traumatic brain injury) 0. No 1. Yes 9. Do not know/ Not sure	

64b. Did your child ever have brain infection (meningitis/encephalitis) during which he/she had altered sensorium/loss of consciousness and/or seizures along with fever? (Post natal brain infections) 0. No 1.Yes (Specify the reason if known_____) 9. Do not know/ Not sure	