DISSERTATION TITLE

"Prevalence and associated risk factors for Epilepsy and Neuromotor impairments among rural children aged 2-9 years in Palwal (Haryana)"

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

Postgraduate Programme in Hospital & Health Management

By

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New Delhi

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Acknowledgement

Public health is a diverse & growing field of study in India. An important challenge today is rural health. There needs to be equal emphasis on rural health practice with a clear vision of reaching the unreached. With these thoughts in mind we came to INCLEN.

We are graciously and heartfelt thank to Dr. Narendra Kumar Arora sir (Executive Director, INCLEN, New Delhi).

He provided his supportive guidance to make the completion of this project a success.

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We would also like to thank to Dr. Rajesh bhalla (Dean - Academic & Student Affairs IIHMR New Delhi), for his kind support during our training.

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Certificate from Dissertation Advisory Committee

This is to certify that **Dr. Sheetal Prakash Vyas**, 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 Epilepsy and Neuro Motor Impairments 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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April 15th, 2012

Certificate of Internship Completion

This is to certify that Dr. Sheetal Prakash Vyas 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

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Certificate of Approval

The following dissertation titled "Prevalence and associated risk factors for Epilepsy and Neuromotor impairments among rural children aged 2-9 years in Palwal, 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

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Chapter 5

ABBREVIATIONS

ADHD	Attention Deficit Hyperactivity Disorder
ASD	Autism Spectrum Disorder
CCC	Consensus Clinical Criteria
CP	Cerebral Palsy
ICIDH	International Classification of Impairments, Disabilities and Handicaps
ICR	Intelligent Character Recognition
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	Ototacoustic Emissions

Part1: Internship Report

1.1 Organization profile

INCLEN TRUST INTERNATIONAL

INCLEN 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 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 creation of INCLEN trust: "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."

- D.W. Fraser".

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 INCLEN 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: "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."

Our slogan:

"Research and training for improving equity, efficiency and quality in health care."

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.

Values

- **Overarching Goal**: Improved Health of People.

- **Beneficiaries**: Individuals, Communities, Disadvantaged populations, Developing Countries.
- **Underlying Value:** Equity .
- **Network Characteristics:** Collegiality, Sharing Knowledge, Mutual Support, Collaboration, Partnership," Friends-Helping-Friends", Bridge-building.

Desirable Outputs: Commitment to quality, Efficiency, Effectiveness, "World Class outputs, Multidisciplinary in content and process, Capacity for teaching / training, Multicenter clinical trials.

Desirable Impact: Significant contribution as a network, Policy relevant, Advice to government, Research to Policy, Implementation and action.

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.

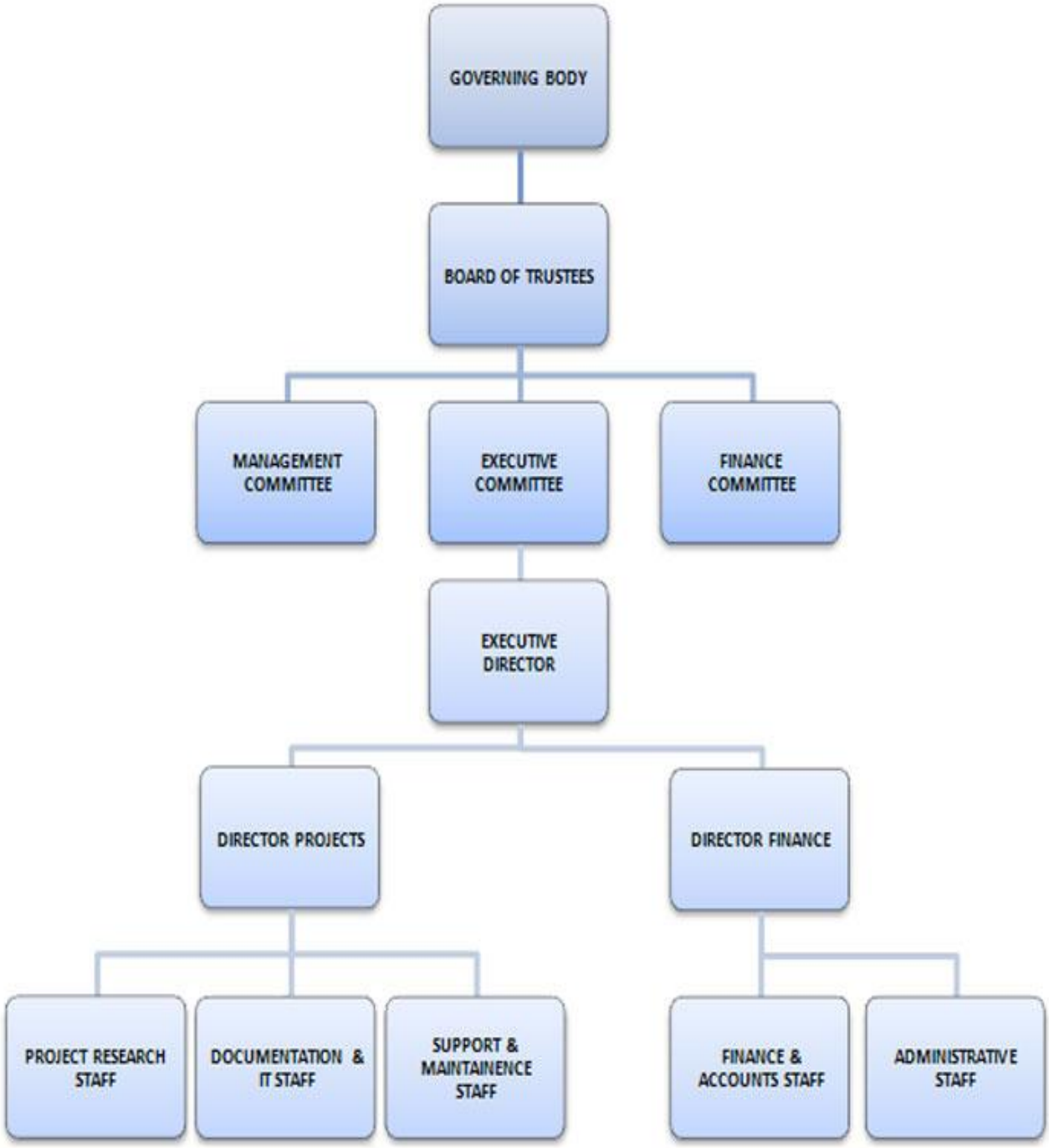
At regional level, INCLEN regional networks apply strategic approaches to health problems and training needs while linking with governments and other agencies to promote change.

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 Goal:

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.The Management Committee

1.2 Where we were engaged-

During my internship period I was appointed as a Research Fellow for Neurodevelomental disabilities Study in Palwal District (Haryana). I worked for Project "Neurodevelomental disabilities among children in India and prevalence of Epilepsy, Neuromotor Impairments and their associated risk factors among children aged 2-9 years in Hathin block of Palwal (Haryana)

1.3 A brief report on managerial tasks

MANAGERIAL DUTIES AND TASKS PERFORMED

Following were the duties assigned to me:

- Technical and managerial support to the study for capacity building
- Community engagement
- Aware Community for participation in study.
- Manage team of 4 Field officers and task assignment to them.
- Advance Planning for Next week work assignment to team mates
- Problem and Issue, queries solution of team mates.
- Community Mobilization of 10 villages.
- Meeting with ASHA, ANM, AWW for the orientation regarding the NDD Study and collected data of pregnant women, new born, and Infants of individual villages..
- Tool development e.g. Infant screening form, New Born Record Form, Identification of Pregnant women & Infant Form, Repeat Clinical Record Form, Socio Economic Status Scale (SES),Weekly Home visit Record Form, Training Modules for Parents, Training Modules for Health Workers, Log sheet for Pregnant Women, New born and Infant. Questionnaire on Consumer Awareness regarding the adverse effect of soft drinks on health at Palwal.
- Preparation of ICR, Log sheets, reporting sheet and Manpower activity sheet on weekly basis and submitted to Admin department, Field Office.
- Monitoring and supervision of Study
- Daily reporting to Shrinager Office.
- Strengthen the micro planning at the ground level.
- Identifying key Risk Factors which is associated to Neurodevelopmental diseases.
- Daily Field visit for check of Quality data with 100 % accuracy.
- Increase the awareness at community level towards the various communication drives.
- Evaluation of Data on weekly basis and target plan according to that.

1.4 Learning Points. . . . . .

REFLECTIVE LEARNING

1. The internship period was definitely a great learning experience for me. It gave me hands-on experience in the field of public health. I got to know the various aspects of NDD study:

Basic understanding of Field activity through NDST-B filling in 25 clusters,

- Documentation: Understanding of various records such as Technical manager daily report sheet, field Report sheet.
- Community Liaison, rapport building,
- How to use channel of ASHA workers, AWW, and ANM.
- Logistics management.
- Procurement Management
- Team building and Leadership

2. **Team management**:

The management of the field activity with the field officers, have weekly meeting where issues from the field discussed. During these meetings the major decisions affecting field work were discussed.

3. **Field team meetings**: For effective management of field work meeting of all the field officers and Hospital Team of Shrinager. Progress of work and target completion was also discussed with them in alternate and weekly meetings at shrinager office of Inclen.

Part 2: Dissertation on

"Prevelence and associated risk factors for Epilepsy and Neuromotor- impairments among rural children aged 2-9 years in Palwal (Haryana)"

Chapter 1

Introduction- Background and Overview

A neurodevelopmental disability or disorder of neural development, is an impairment of the growth and development of the 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 and that 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 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 judgement of mental and physical functioning of the body and its

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 fulfillment of a role that is normal (depending on age, sex, and social and cultural *factors) for that individual.*

component parts according to accepted standards. The classification of impairment is hierarchical, allowing considerable specificity for those needing to record such detail.

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.

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

According to WHO, Epilepsy is one of the most prevalent neurological disorders that can be effectively prevented and treated at an affordable cost. It is the most common serious brain disorder worldwide with no age, racial, social class, national nor geographic boundaries.

- There are over 50 million sufferers in the world today, 85% of whom live in developing countries;
- An estimated 2.4 million new cases occur each year globally;
- At least 50% of cases begin at childhood or adolescence;
- 70% to 80% of people with epilepsy could lead normal lives if properly treated;
- In developing countries, 60% to 90% of people with epilepsy receive no treatment due to inadequacies in health care resources and delivery, and due to social stigma.

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 1 (A): 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 1 (B): 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); Locomotor 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

Indian context-

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 locomotor 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.

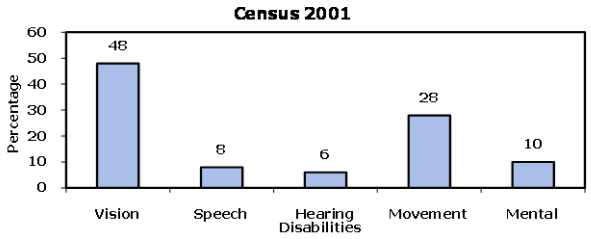
Estimates of Disability in India by Census and NSSO

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

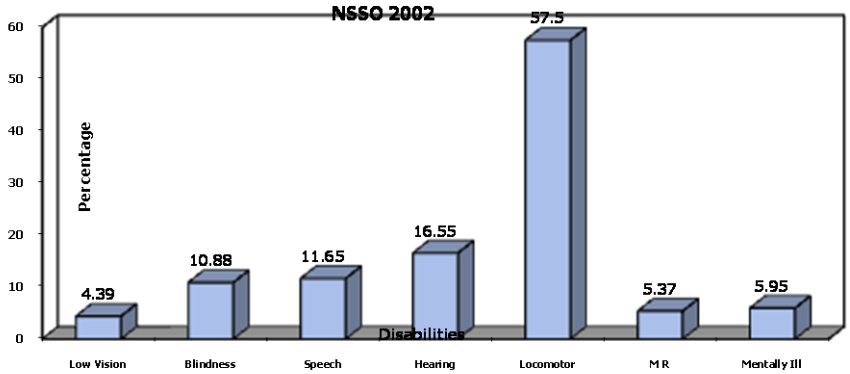
In a recent survey of 579 school children aged 6–10 years in the state of Kerala, India estimated the prevalence of sub-normal cognition at 9.5% and abnormal cognition at 2.9%

Disability in India (All age groups); census 2001



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

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 2: Risk Factors for developmental disabilities in developing versus developed countries.

Developing countries	Developed countries
Infection*	Severe, often previously fatal chronic disorders**
Malnutrition*	Behavioral/ emotional disorders**
Developmental problems of organic pathology**	Socioeconomic disadvantage among the 'have-nots'*
Sanitation, water supply, food hygiene, housing & education*	Drug abuse, smoking, teenage pregnancies*;
Environmental toxins*	Genetic factors
Poverty/ unemployment*	
Health care*	

High birth rate*, consanguinity*, single mother*, attempted abortions*, younger age at marriage*; perinatal / neonatal factors*; Genetic factors	
*Modifiable risk factors	
** Some modification possible	

Inclen proposes to conduct this study with the aim of highlighting the problem of NDDs among children and collecting information on determinants that have the potential to design culturally appropriate interventions and reduce burden of NDDs in India with wide applicability in other low and middle-income countries.

The primary objective of this study is to assess the prevalence of ten (10) common neuro-developmental disabilities (NDDs) among children aged 2-9 years in India. NDDs included in the study are; Attention-deficit/hyperactivity disorder (ADHD), Epilepsy, Learning Disorders (LD), Intellectual Disability (ID), Neuromotor Impairments including cerebral Palsy (CP), Autism Spectrum Disorders (ASD), Speech and Language Disorders, Hearing Impairment (HI) and Vision Impairment (VI).

This was a cross sectional community based study. NDST validation will be carried out in four strata; rural, urban, hilly and tribal across 5 sites in India. At each site, 1000 children will be assessed except in Goa 500 children will be assessed. Study population will comprise of children between 2 to 9 years of age. The first phase of this study is continuing. We have taken some part of this study which is primarily focused on two Neuro-developmental disabilities including Epilepsy, Neuro-motor Impairment and their associated risk factors.

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 Neuro-developmental disorders including cerebral palsy, epilepsy and those with multiple disabilities is also needed so as to suggest 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. So it is important to estimate the prevalence of and associated risk factors of NDD. Keeping in view the above thrusts we propose to conduct this study with overall aim of to assess the prevalence of Epilepsy and NMI including Cerebral Palsy and their associated risk factors among the children in Palwal district.

The purpose of conducting this study is to highlight the problem accompanied with the Epilepsy and Neuromotor Impairments among children aged 2 – 9 years in Palwal. 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.

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 Epilepsy and Neuromotor Impairments 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.

LITRETURE REVIEW

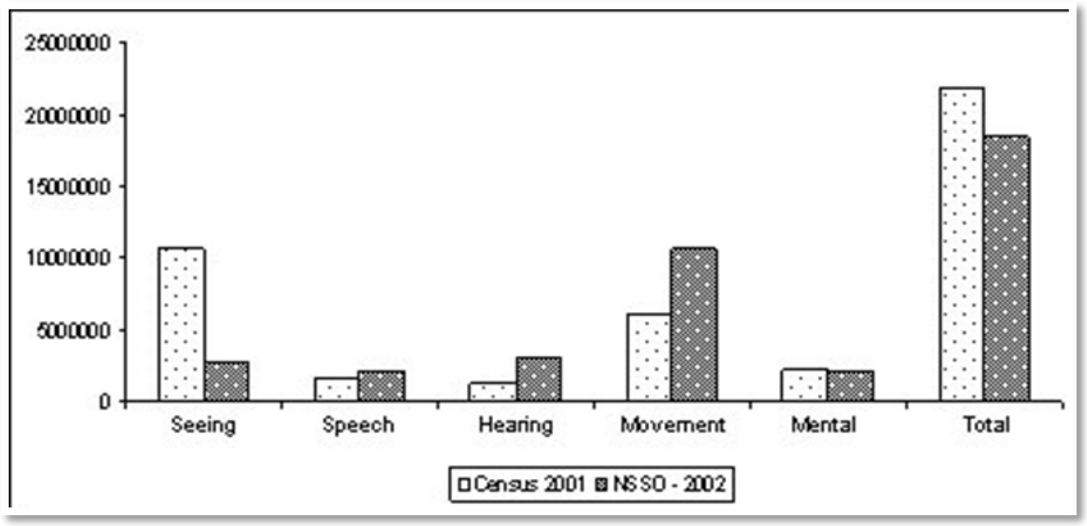
According to the WHO definition Intellectual disability can be defined as a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence). This results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development.

Disability among children is the crucial area where the attention has been demanded. Disability depends not only on a child's health conditions or impairments but also and crucially on the extent to which environmental factors support the child's full participation and inclusion in society. 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.

WHO estimates that worldwide 15-20% of children have disabilities and Kohler et al suggest a prevalence of 5-20% [(3)]. A comprehensive India-wide sample survey undertaken by National Sample Survey Organization (NSSO) in 2002 reported a prevalence of disabilities to be 1.8% [(4)].

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 locomotor 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.

In India, the discrepancy has been evidenced in the two available data sources Census 2001 and NSSO 2002 regarding the prevalence of individual disabilities. However, a recent survey of 579 school children aged 6–10 years in the state of Kerala, India estimated the prevalence of sub-normal cognition at 9.5% and abnormal cognition at 2.9%.



A descriptive cross sectional study was conducted on predictors of care giver stress in families of pre-school aged children with developmental disabilities. 125 Mothers of pre-school aged children with developmental disability completed assessment measures addressing the key variables .Analysis demonstrated that the difficulty the parents experienced in completing specific care giving tasks , behavior problems during these care giving tasks and level of child disability were significant predictors of level of parental stress. Mother's level of social and family support had a moderating effect on the relationship between key independent variables and level of parent stress[13].

A study was conducted on the developmental delay and disability among 0-5 age group children in 2009 at Alappuzha, in Kerala, India.They conducted this study to assess the prevalence of developmental delay, deformity and disability among 0-5 age group children in Pattanakkad rural ICDS block, selected at random from among the ICDS blocks in Alappuzha district. Of 12520 children up to 5 years in this block, there were a total of 311 children with developmental delay, deviation, deformity or disability giving a prevalence of 2.5 % (95 % CI, 2.22 to 2.77). The prevalence of developmental disabilities up to 2 years was 2.31 (95 % CI, 1.91 to .71) and

from 2 to 5 years 2.62 % (95 % CI, 2.25 to 2.99). The prevalence obtained in the study has important policy implications for identifying childhood disabilities in the community.

A descriptive, co relational, cross-sectional study was conducted on the relationships among adaptive behaviors of children with autism, family support, parenting stress and coping. The study was conducted on 75 primary care givers of children with autism. Tool used was Mc Cubbin and Patterson Model of family behavior to measure adaptive behaviors of children with autism, family support networks, parenting stress and parents coping. They found that an association exists between the low adaptive functioning in children with autism and increased parenting stress creates a need for additional family support as parents search for different coping strategies to assist the family with ongoing and new challenges[22].

A descriptive study was conducted on the health of primary care givers of children with cerebral palsy. The goal of this study was to compare the physical and psychological health of care givers of children with cerebral palsy (CP) with that of the general population of Care givers (CGs) . Data on the physical and psychological health of 468 primary Care givers s of children with CP, drawn from 18 of 19 publicly funded children's rehabilitation centers in Ontario, Canada, were collected with a self-completed questionnaire and a face-to-face interview. Identical items and scales had been administered previously to nationally representative samples of the Canadian population in 2 large-scale Canadian surveys, i.e., the National Population Health Survey (NPHS) and the National Longitudinal Study of Children and Youth (NLSCY). NLSCY (n = 2414) and the NPHS (n = 5549).Measures of support showed no difference in reported social support or family functioning (CG: mean score: 8.6; SD: 5.6; NLSCY: mean score: 9.0; SD: 4.9) between the 2 samples, although the CG sample did report a statistically greater number of support contacts (CG: mean score: 4.5; SD: 0.7; NPHS: mean score: 4.2; SD:

0.9). Measures of psychological health showed greater reported distress (CG: mean score: 4.7; SD: 4.4; NPHS: mean score: 2.2; SD: 2.7), chronicity of distress (CG: mean score: 5.5; SD: 1.4; NPHS: mean score: 5.2; SD: 1.1), emotional problems (CG: 25.3% indicating problems; NPHS: 13.7%), and cognitive problems (CG: 38.8%; NPHS: 14.3%) among CGs of children with CP. They also reported a greater likelihood of a variety of physical problems·

Objectives of the Study

General Objective

This cross sectional study aims

- To document the prevalence of two common neuro-developmental disabilities (NDDs)/disorders (Epilepsy and Neuro-motor 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 Epilepsy among rural children aged 2-9 years in Palwal district of Haryana
- To document the prevalence of Neuromotor impairments 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

1. The estimated prevalence of Epilepsy and Neuromotor impairments in children ages 2-9 in rural area of Palwal would be useful for policy making.
2. 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.

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 neurodiasbilities 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 Epilepsy and Neuro-motor impairments 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

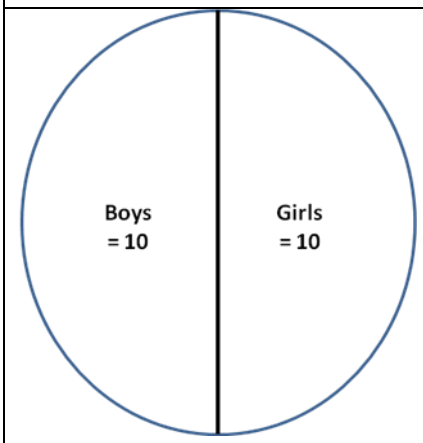
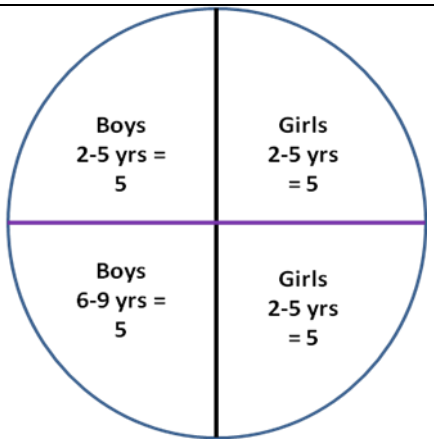
Census data (2001) (Registrar General of India) will be used for selecting clusters. For each district (study site), Census data will be arranged in three columns, with list of names of villages/administrative wards (sampling unit) in the first column, total population of that unit in the second column and cumulative population in the third column (which is obtained by adding the population of all preceeding 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.

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, 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, 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

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.

NDST has three sections; Section I (details of the child and demographic information), Section II (screening questions for ten NDDs) and Section III (information on known risk factors). Selected children were screened using specific NDST.

NDST was used by us for screening children and it has three sections-

- Face sheet with the subject's identity
- Section I - NDST
- Section II - Potential risk factors

Secondary data was collected from:

- Published Literature on websites
- Inclen library, records

2.6 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.

Implemented plan

Step 1: Cluster Listing

Step 2: Data Collection

Step 3: Data Entry

Step 4: Data Analysis & Report Writing

All the filled questionnaires that were reviewed in the field would be scrutinized before being entered. Analysis of the quantitative data was carried out with the help of SPSS 16.0. Analysis plan and dummy tables would be prepared before the ending of Questionnaires.

Chapter 3

Results and findings –

General Findings-

This chapter gives the findings on profile of households and details of prevalence of epilepsy and Neuro-motor impairments and their associated risk factors in Hathin block.

As mentioned in the methodology chapter, a total of 100 family members of households having 2-9 years of children of villages were interviewed in their respective groups.

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3.1 PROFILE OF RESPONDENTS AND THEIR CHILDREN

This section presents the profile of the respondents covered in the study:

Age distribution of children-

Table 3.1a presents the age distribution of the children (children of households of different clusters of Hathin block). 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.

Table 3.1a Age distribution of children

Age category	Number	Percent
2-<6 Years	50	50.0
6-9 Years	50	50.0
Total	100	100.0

Sex distribution of children-

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

Table 3.1b Distribution of respondents by sex

Sex of Child		
Sex	**Number**	**Percent**
Male	**50**	**50**
Female	**50**	**50**
Total	**100**	**100**

Study involved respondents of both sexes equally (50% male & 50% females).

Educational attainment-

Table 3.1 gives the educational attainment of 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.

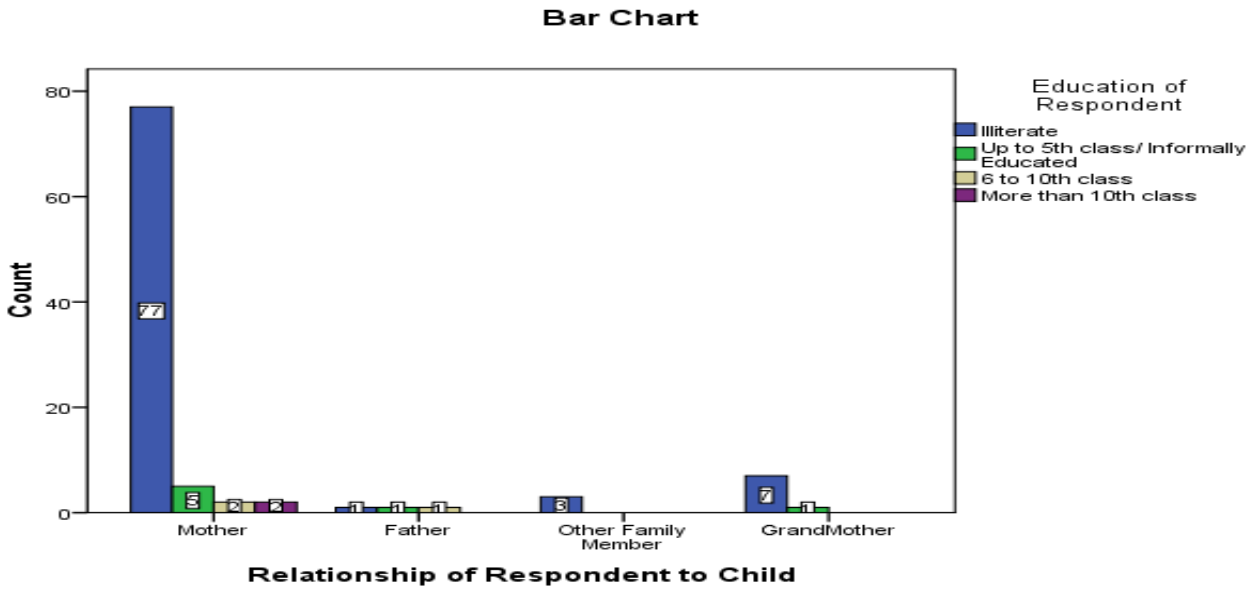
Table 3.1c Distribution of respondents by educational status

Education	Number	Percent
Illiterate	88	88.0
Up to 5th class/ Informally Educated	7	7.0
6 to 10th class	3	3.0
More than 10th class	2	2.0
Total	100	100.0

Education of different family members including females

Out of total Mothers 77% mothers are illiterate and only 2% mothers are educated with the qualification of more than class 10^{th}.

Figure 3.1d Education of different family members including females



Relationship of Respondent to Child

Table 3.1e Relationship of Respondent to Child

Relationship	Frequency	Percent
Mother	86	86.0
Father	3	3.0
Other Family Member	3	3.0
Grandmother	8	8.0
Total	100	100.0

3.2 Details of Possible Disabilities in children in Hathin block made by hospital team

Prevalence of epilepsy in selected 5 Villages of Hathin block-

Out of the total of 100 respondents, only 5 percent of the children have the possibility of having the epilepsy while about 95 percent of the respondents are the ones who do not have the epilepsy.

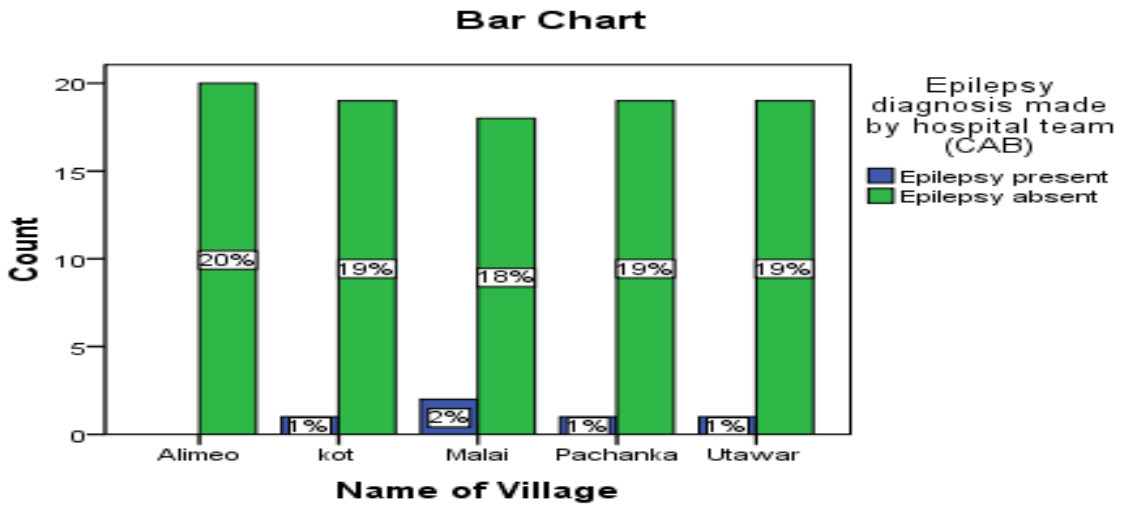
Table 3.2a Total Prevalence of epilepsy in Hathin block

	Diagnosis	Number	Percent
Valid	Epilepsy present	5	5.0
	Epilepsy absent	95	95.0
	Total	100	100.0

Total Prevalence of epilepsy (diagnosed by hospital team) is 5% in 5 villages of Hathin block of Palwal.

Prevalence distribution of epilepsy in selected 5 Villages Hathin block

Figure 3.2b Total Prevalence of epilepsy in Hathin block by villages



Prevalence of epilepsy is highest in Malai village amongst the surveyed villages of Hathin.

Prevalence of Neuro-motor impairments in selected 5 villages of Hathin block-

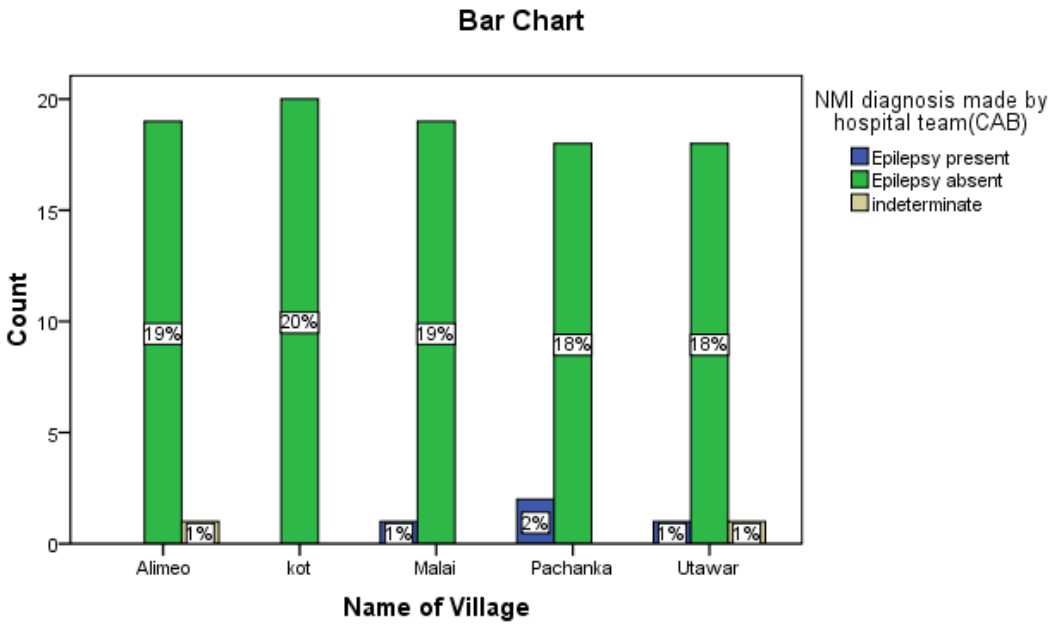
Table 3.2c Total Prevalence of NMI in Hathin block

NMI diagnosis made by hospital team(CAB)			
	Diagnosis	Number	Percent
Valid	Possible disability present	4	4.0
	Possible disability absent	94	94.0
	Indeterminate	2	2.0
	Total	100	100.0

Total prevalence of Neuro motor impairments is 4% in 5 villages of Hathin block.

Prevalence distribution of Neuro-motor impairments in 5 selected villages of Hathin block

Figure 3.2d Total Prevalence of NMI in Hathin block by villages

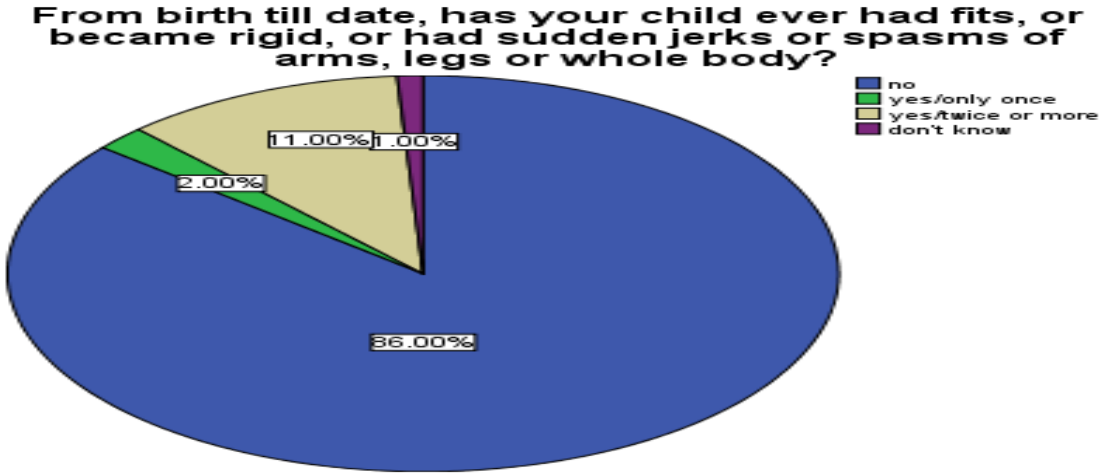


Amongst the 5 villages of Hathin, Pachanka village had the highest cases of NMI disorders.

3.3 Specific findings related to Epilepsy and NMI-(through diseases related questions)

3.3a (1) Children having Epileptic symptoms-

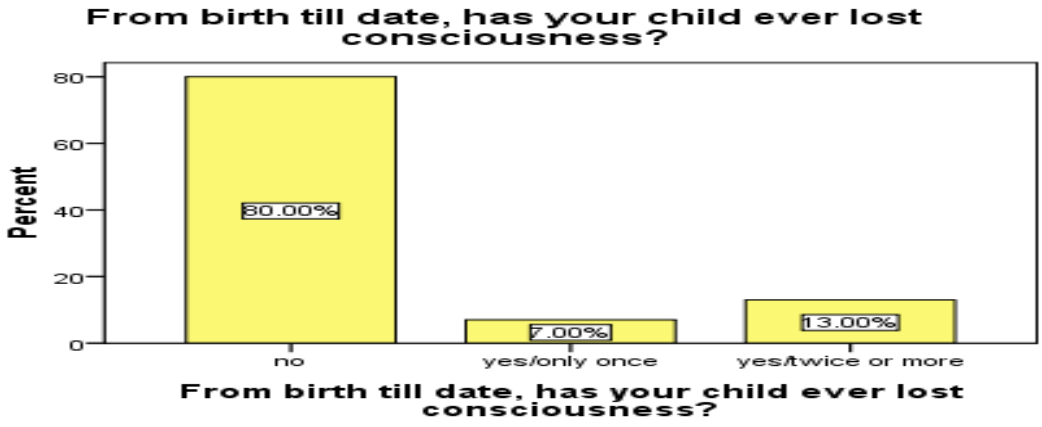
Figure3.3a (1) Children having jerk/fits/rigidness/sudden jerks or spasms of arms, legs or whole body.



Amongst the 5 villages of Hathin, 11 % of parents admitted there children having experienced jerk/fits/rigidness/sudden jerks or spasms of arms, legs or whole body.

3.3b (1) Children having Epileptic symptoms-

Figure3.3b (1) Children had experienced loss of consciousness twice or more from birth till death.

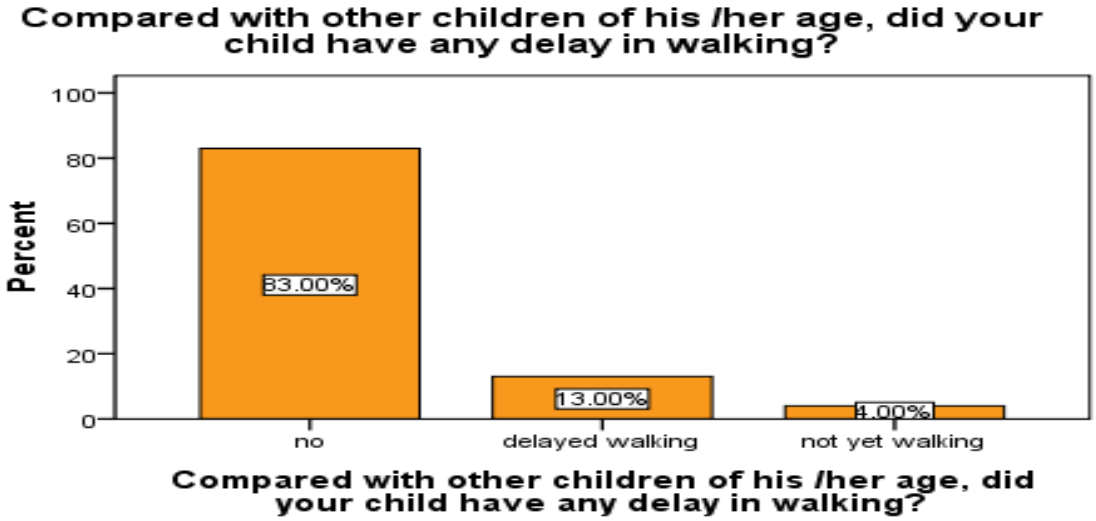


Amongst the 5 villages of Hathin, 13 % of parents admitted their children have experienced loss of consciousness twice or more from birth till death.

3.3a(2) Children having symptoms of Neuromotor impairments -

A) Children having Problem of Delayed Walking-

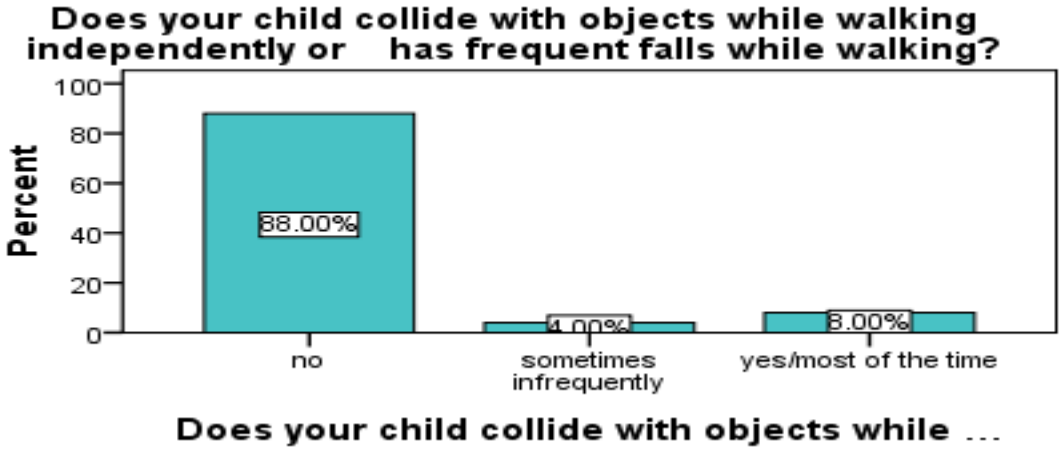
Figure3.3a (2) children having problem of delayed walking



Amongst the 5 villages of Hathin, 13% of children have had problem of delayed walking.

B) Children having Problem of Improper walking-

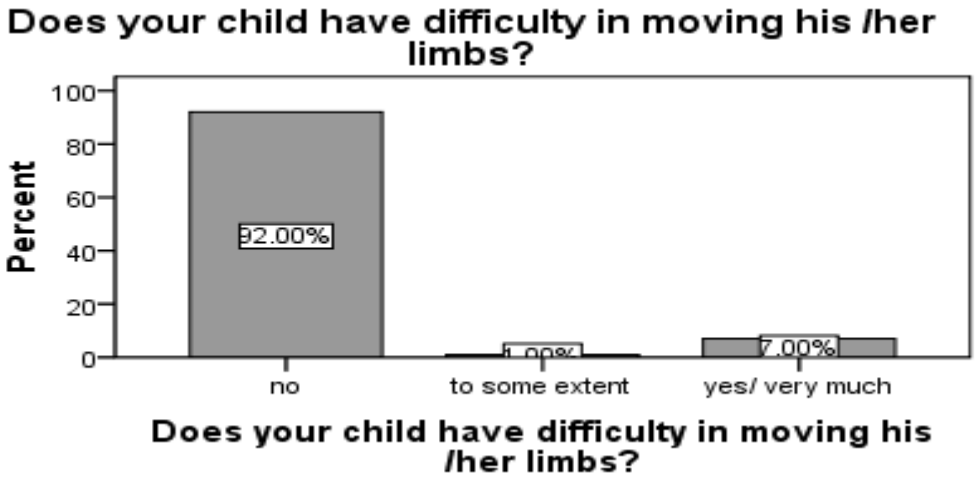
Figure3.3b (2) children having problem of improper walking



Out of 5 villages of Hathin, 8% of children have had problem of improper walking.

c) Children having Difficulty in Moving limbs –

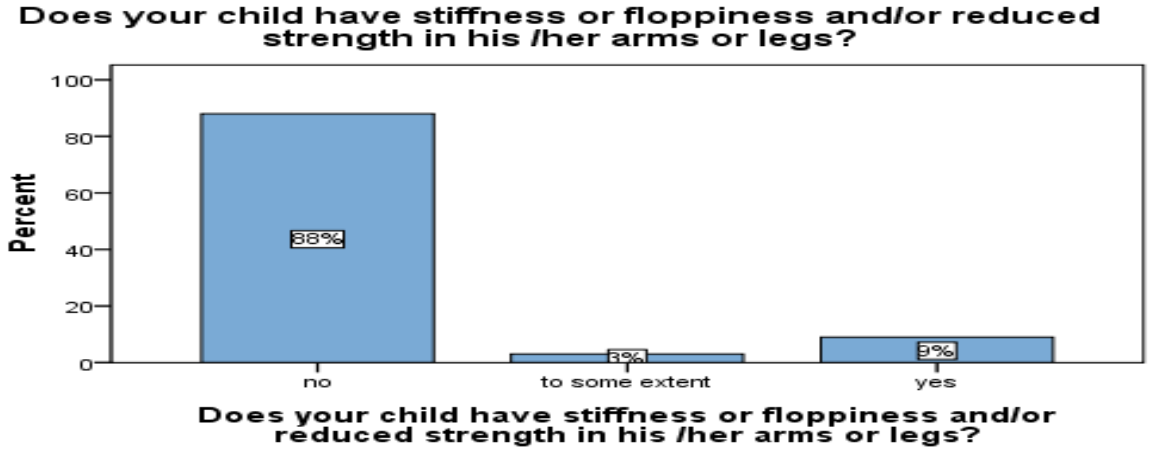
Figure3.3c (2) children having difficulty in moving limbs



Amongst the 5 villages of Hathin, 7 % children had problems in moving their limbs.

D) Children having problem of stiffness/floppiness or reduced strength of limbs –

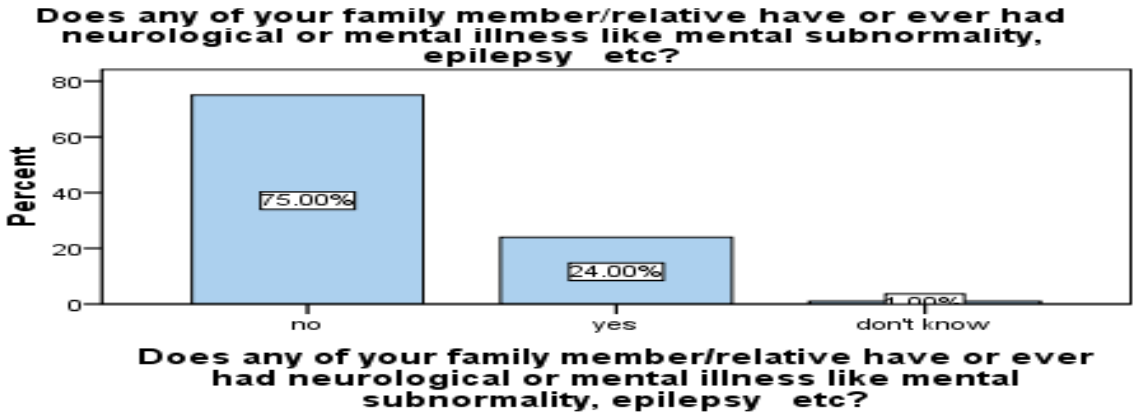
Figure3.3d (2) children having problem of stiffness/floppiness or reduced strength of limbs



Amongst the 5 villages of Hathin, 9% children have problems of stiffness or floppiness and reduced strength in their limbs.

3.4) Risk factors for Epilepsy and NMI-

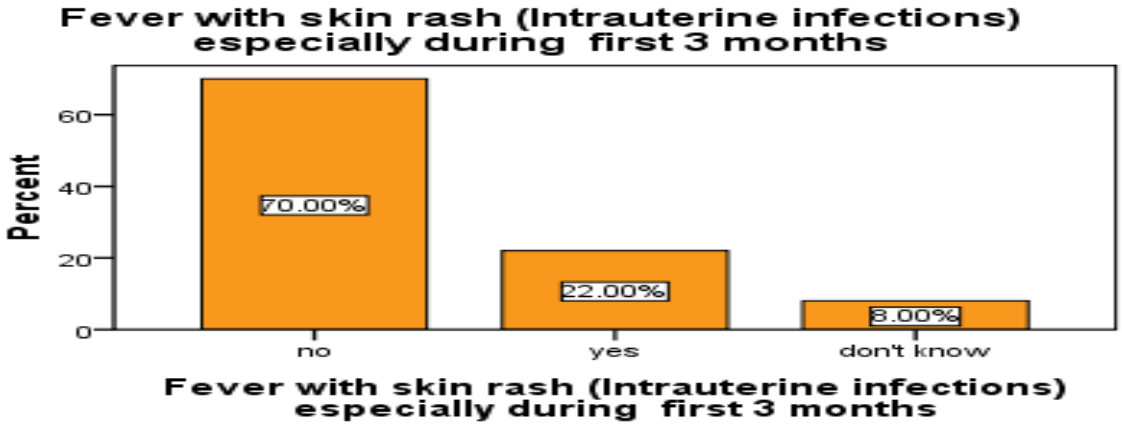
3.4a History of family members having neurological problem



24% of the relatives of respondents have mental illness like mental sub normality, epilepsy etc amongst the surveyed 5 villages of Hathin.

3.4b History of Problems during pregnancies-

3.4b (1) History of Intrauterine Infections during pregnancy-

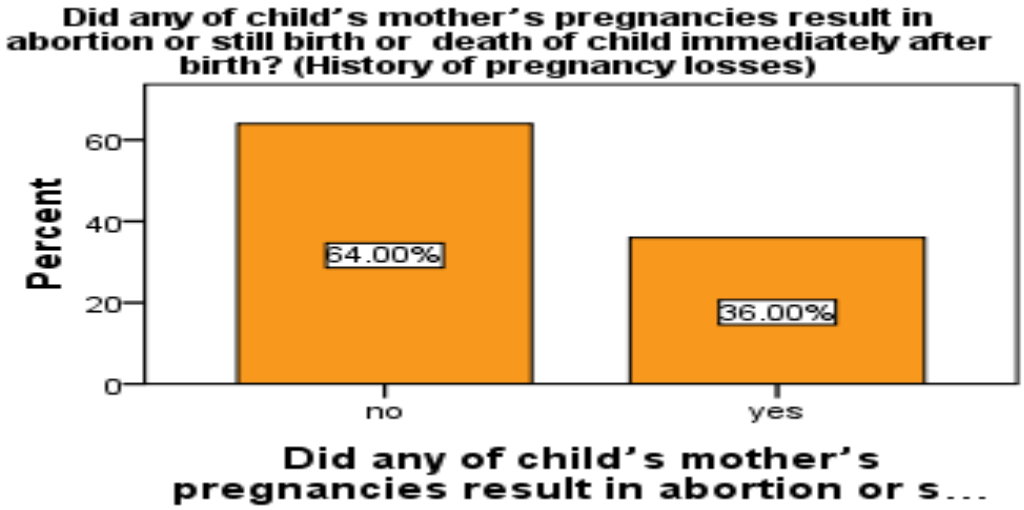


Out of total, 22% females have complained of intrauterine infections.

3.4b (2) History of abruptio placentae during pregnancy-

Out of total, 6% females have complained of intrauterine infections. We do not explain whether it is Induced or not.

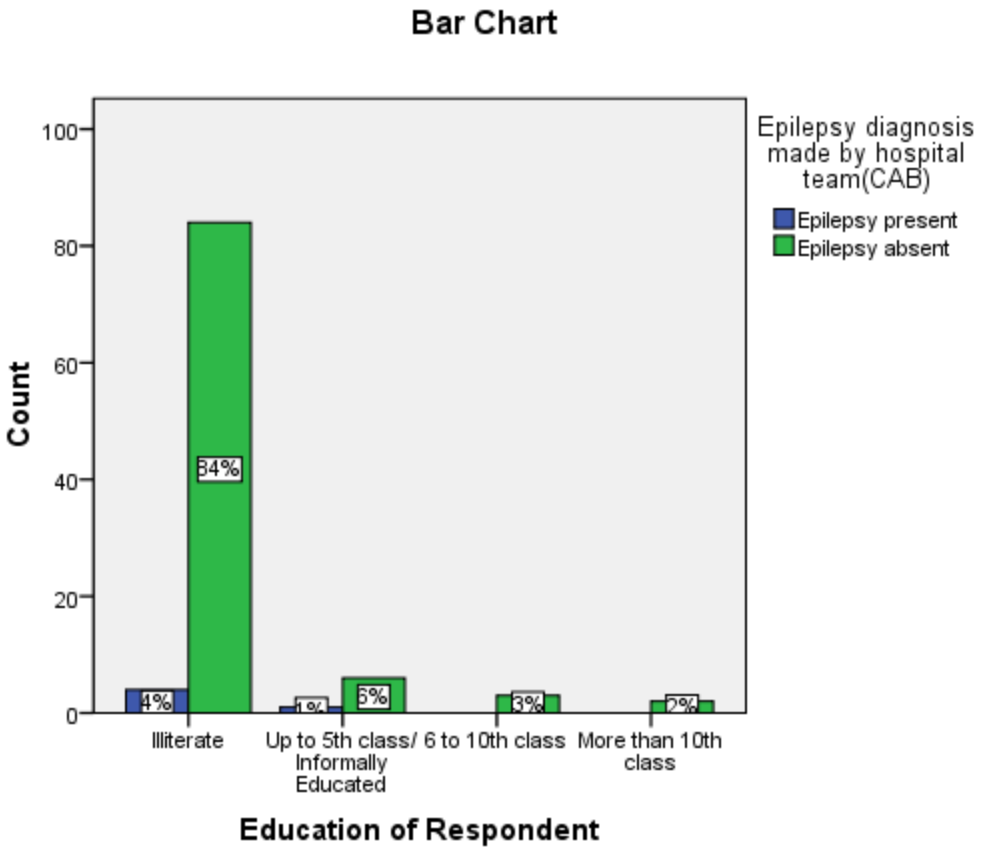
3.4b (3) History of Pregnancy Losses-



36% of females have experienced pregnancy losses in the past.

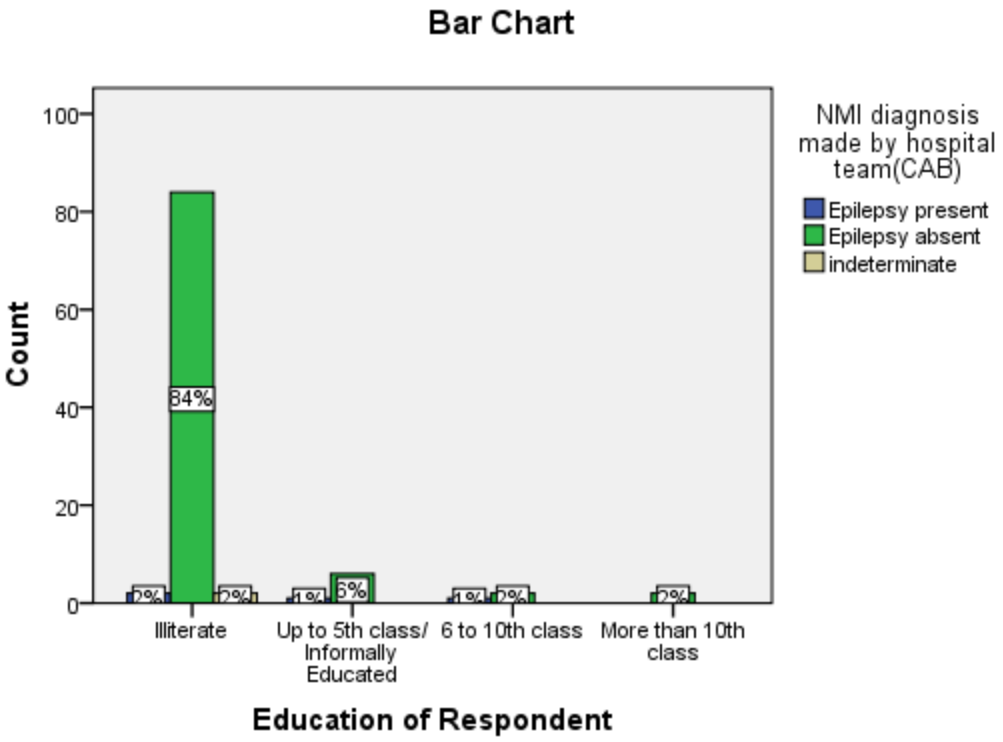
Discussion:-

(4.1a) Association between Education & Epilepsy)



According to the study data there is no association between literacy and epilepsy and 4% prevalence have found in the children of these illiterate category. It may be possible that 4% epilepsy cases due to clustering of multiple risk factors in the illiterate people because they are living in poor, unhighgenic conditions so they are more vulnerable to these diseases.

(4.1b) Association between Education and NMI

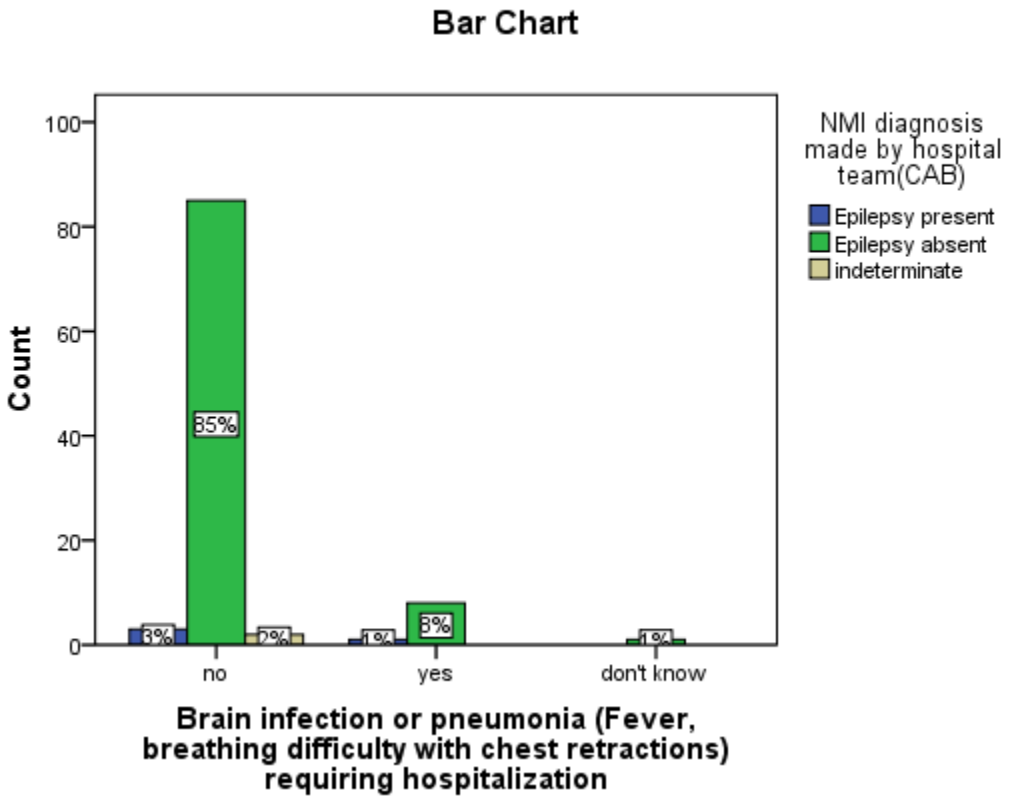


According to the study data there is no association between literacy and Neuro motor impairments. Only 2% prevalence have found in the children of these illiterate category.

It may be possible that 2% NMI cases due to clustering of multiple risk factors in the illiterate people because they are living in poor, unhighgenic conditions so they are more vulnerable to these diseases.

4.2 Associated risk factors for Epilepsy and NMI-

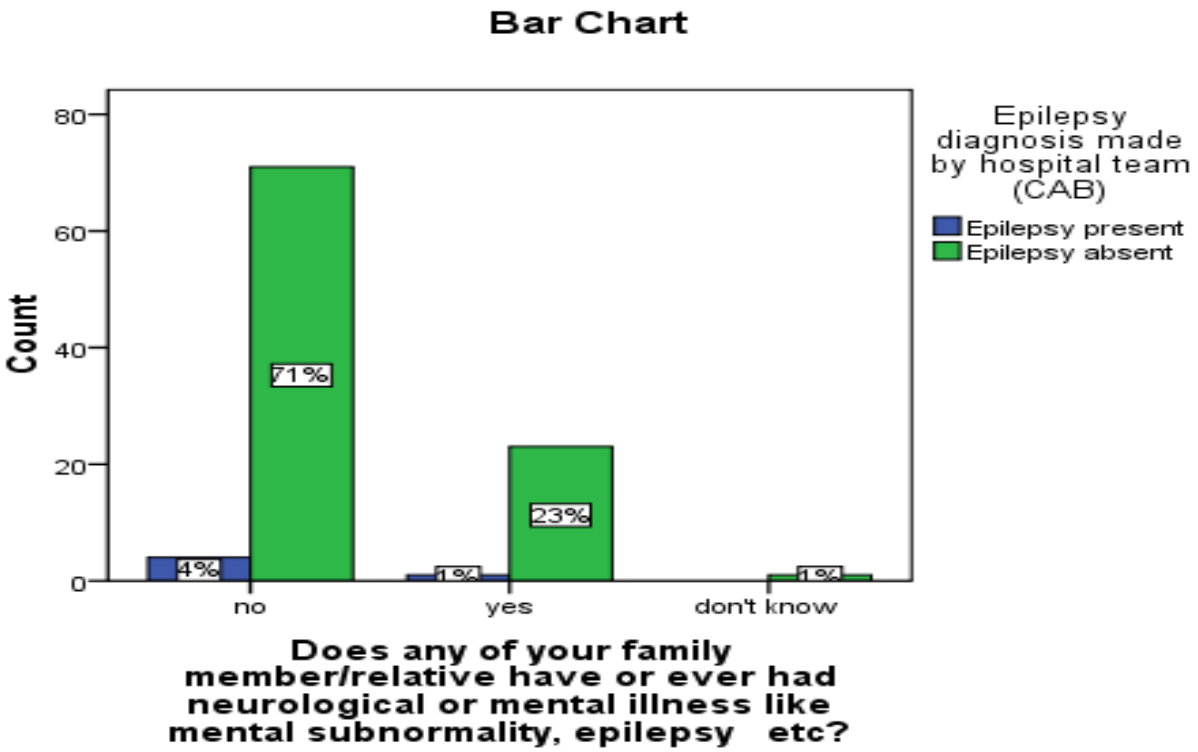
4.3b History of Post natal brain infections/pneumonia/asphyxia in a child and NMI-



Among the respondents who have said there is no History of brain infections/pneumonia/asphyxia in their children 1 % of them still have found out to have NMI in children and similarly out of the respondents Who have said there had some complaints of brain infections/pneumonia/asphyxia in their children 1 % in them still have found out to have epilepsy.

Out of four Neuromotor impaired children one suffered with post natal brain infection during which he/she had altered sensorial/loss of consciousness and/or seizures along with fever. So it means brain infection may lead to NMI. It has been clearly depicted in above given Figure 4.3b.

4.2a History of neurological problem in family members and epilepsy



Among the respondents who have said there is no neurological problems in their family members 4 % in them still have found out to have epilepsy and similarly out of the respondents Who have said there is some neurological problems in their family members 1 % in them still have found out to have epilepsy.

Limitations and Challenges

1. The small sample size is one of the major constraints in the study. The sample size is 100 children in total.
2. The data has been collected from five villages of Hathin block of district Palwal. This area is primarily of Muslim religion. Respondents, being from these areas are having very low literacy level.
3. The time constraint of around 3 months is another limitation for the study.
4. Lack of cooperation by study subjects and their care providers.

Expected Outcomes-

1. The prevalence of Epilepsy and Neuromotor Impairments among children aged 2-9 in rural areas of Palwal will be estimated.
2. Potentially modifiable risk factors according to region will be identified.
3. Development of strategies so as to help in efficient allocation of resource and effective policy formulation.
4. Data so generated will be mapped against existing facilities for diagnosis/management and rehabilitation of children with Epilepsy and Neuromotor Impairments.

Chapter 5

Conclusion-

In this study, a lot of risk factors were identified which contribute to Epilepsy and Neuro-motor impairments. 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.
- In the selected 5 villages of Hathin the percentage of illiterate people was high. Only 2 percent respondents are educated with qualification More than 10th class. Out of total Mothers 77% mothers are illiterate and only 2% mothers are educated with the qualification of more than class 10^{th}.
- Study depicts that total Prevalence of epilepsy (diagnosed by hospital team) is 5% in 5 villages of Hathin block of Palwal. Prevalence of epilepsy is highest in Malai village amongst the surveyed villages of Hathin.
- Data of study shows that prevalence of Neuro motor impairments is 4% in 5 villages of Hathin block and amongst these villages of Hathin; Pachanka village had the highest cases of NMI disorders.
- Data on prevalence and spectrum of NDDs in the community and potentially modifiable risk factors may be used for advocacy and enable policy makers in rational allocation of adequate resources for prevention, treatment and rehabilitation of the neuro-developmentally disabled.

RECOMMENDATIONS:

- The system should be family centered 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 Epilepsy and NMI.
- Appropriate interdisciplinary intervention programs for children suffering from these diseases and their families should be counseled regularly. Intervention programs should recognize and build on strengths, informed choices, traditions, and cultural beliefs of the families.
- Branch Office Shrinager should be established with full facilities instant internet connectivity, power back up, and Pure Water facilities, and also guest room.
- Proper hierarchy should be maintained.
- Job description and reporting pattern should be properly clear to each staff- member..
- Involvement of community should be appreciated and after end of entire activity, helper villagers should be rewarded.
- Weekly assessment should be done of field officer on the basis of performance of their respected team.
- Interview must not be taken in a hurry.
- Specific Management problem: Branch Office Shrinager village has not been set up properly. It has lack of infrastructure.
- Communication gaps should not occur between incharge of field site and FW.
- Sudden change in activity may affect efficiency of work so prior information about this should necessary given to the field teams.
- Team division should be based on performance of FW.
- Priority should be given to those FW who are from that village or adjacent village.
- Incentives should be given to hard working FW

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14. GLOSSARY

Attention-deficit/hyperactivity disorder (ADHD) refers to a constellation of inappropriate behaviors found in many children and adults. Children with ADHD have trouble paying attention in school, at home or at work. They may be unusually active and/or impulsive for their age. These behaviors may contribute to significant problems in relationships and learning. The essential feature of Attention-deficit/hyperactivity disorder is a persistent pattern of inattention and/or hyperactivity-impulsivity that is more frequently displayed and more severe than is typically observed in a child at comparable level of development. There is no single, comprehensive and concise definition of ADHD. The Diagnostic and Statistical Manual of Mental Disorders, 4th edition (DSM-IV; American Psychiatric Association, 1994) defines three specific elements of ADHD are Inattention, Impulsivity and Hyperactivity.

Cerebral palsy (CP) is a neuro-developmental disability characterized by motor disability (palsy) caused by a static, non progressive pathology in the brain (cerebral). The causative event has to occur in early childhood, (usually below 2 years of age). It describes a group of disorders of development of movement and posture, causing activity limitation, attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, cognition, communication, perception and/or by a seizure disorder.

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.

Epilepsy: It is usually defined as a condition characterized by recurrent (two or more) seizures at least 24 hrs apart, unprovoked by any immediate identifiable cause.

Disability: Defined 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**.**

Hearing Impairment-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.

Inter-rater Reliability: It measures repeatability. It is a method of measuring reliability by determining the extent to which two or more raters obtain the same result when using the same instrument on the same subject. For categorical data, consensus is measured as number of agreements divided by total number of observations. The two scores given to same item by different raters are assessed for consistency. The closer the results, the greater will be the Inter-rater reliability of the survey instrument.

Learning Disorder is defined as a disorder in one or more of the basic psychological processes involved in understanding or in using language-spoken or written, which may manifest itself in an imperfect ability to listen, speak, read, write, spell, or to do mathematical calculations.

Intellectual disability (ID): It is defined as significantly sub-average general intelligence, manifesting during early developmental period. Now Mental retardation is being replaced by ID. But American Association on Mental Retardation defines ID in three domains by measuring of intelligence (IQ), adaptive behavior and systems of supports.

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.

Test – retest Reliability: is a way of estimating the reliability in which the same individuals are administered the same instrument on two different occasions within a short time interval by the same researcher. The two scores given to same item on different occasions are then assessed for consistency. The closer the results, the greater will be the test-retest reliability of the survey instrument.

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

Vision impairment (VI) means that a person's eyesight cannot be corrected to a "normal" level. WHO defines “blindness” as a presenting visual acuity in the better eye of less than 3/60, or a visual field of 10 degrees or less and “low vision” as presenting visual acuity in the better eye of less than 6/18 or a visual field of 20 degrees or less.

Annexure1- Study Questionnaire

Neurodevelomental Screening Tool (NDST) B

Doctor -1 ☐

NEURODEVELOPMENTAL DISABILITIES AMONG CHILDREN IN INDIA:

AN INCLEN STUDY

State	
District	

Date of Interview	**D**	**D**	**-**	**M**	**M**	**-**	**Y**	**Y**

Institution/Partner Medical College:

Tehsil	
Village (Cluster)	

Commencing Time	**AM / Pm**	**Hr**		**Min**	
Concluding Time	**AM / PM**	**Hr**		**Min**	

Namaskar, I am from……..……...
Medical College / Partner Organization. I am here with my colleagues to do a survey of Neuro-developmental disorders. We would like to interview you about mental development of your child. Your participation in the survey would contribute to improve health services and other facilities in this district. You are an important stakeholder in this study and therefore we would appreciate if you could spare some valuable time to discuss about your child's mental development. Your responses will be kept confidential and you may choose to stop your participation at any time.

Respondent: Mother / Primary Caretaker of 2-9 year old child.

Name of interviewer **Signature**

Name of Index Child ……..

Father's/Mother's Name:…...……
Respondent's Name…… ……...
Residential Address: ……..
……

Mobile											
Res											

1b. Age (completed months) Years:____ Months:_____

Convert in completed months ☐☐☐

2b. Age category of the child ☐

1. **2 – < 6 years**
2. **6 - 9 years**

3b. Sex

1 – Male

2 – Female ☐

Respondent Information

4b. Relationship of respondent to child: ☐

1. Mother
2. Father
3. Other Family Member
8. Refused to Answer
9. Others (Specify **……..)**

5b. Education of Respondent ☐

1. Illiterate
2. Up to 5th class / informally educated
3. 6th to 10th class
4. More than 10th class
5. Refused to answer
6. Incomplete information/don't know/ not sure

15b. Compared with other children of his /her age, did your child have any delay in walking?

0. No

1. Delayed walking

2. Not yet walking

9. Do not know/ Not sure

P A T T SKIP

IF THE RESPONSE TO

QUESTION No. 15b is "2"

GO TO QUESTION No. 17b

16b. Does your child collide with objects while walking independently or has frequent falls while walking?

0. No

1. Sometimes/ Infrequently

2. Yes/ Most of the time

9. Do not know/ Not sure

JOIN AFTER SKIP to 17b

17b. Does your child have difficulty in moving his /her limbs?

0. No

1. To some extent

2. Yes/ Very much

9. Do not know/ Not sure

18b. Does your child have difficulty in getting up from squatting position or has progressive worsening/ increasing difficulty in walking, running or climbing stairs?

0. No

1. To some extent

2. Yes/ Increasing difficulty

9. Do not know/ Not sure

19b. Does your child have stiffness or floppiness and/or reduced strength in his /her arms or legs?

0. No

1. To some extent

2. Yes

9. Do not know/ Not sure

20b. From birth till date, has your child ever had fits, or became rigid, or had sudden jerks or spasms of arms, legs or whole body?

0. No

1. Yes/ Only once

2. Yes/ Twice or more

9. Do not know/ Not sure

21b. From birth till date, has your child ever lost consciousness?

0. No

1. Yes/ Only once

2. Yes/ Twice or more

9. Do not know/ Not sure

Risk Factors

45b. Were the child's parents related to each other (i.e. blood relation) before marriage?

0. No

1. 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)

(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 (Preclampsia)*

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?

0. 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

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

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