Etiology of Developmental Disabilities in Low Income Countries

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Figure 6.2 Prevalence of Cerebral Palsy, a subtype of motor deficits, in various countries

Prevalence of Cerebral Palsy per 1000 births

- Bangladesh*
- Bangladesh**
- Malawi
- Gambia
- Korea
- England
- England

* rurally population
** urban population
Neurological, Psychiatric, and Developmental Disorders

MEETING THE CHALLENGE IN THE DEVELOPING WORLD

INSTITUTE OF MEDICINE
Causal Pathways for Learning and Developmental Disabilities
COMMUNITY BASED SCREENING FOR NEURO-DEVELOPMENTAL DISABILITIES IN CHILDREN IN A DEVELOPING COUNTRY (India):

An INCLEN Study

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Brain disorders account for over 25% of disease related morbidity.

Lead to life-long disability, significant losses to the work force & stigmatization.

Epidemiological studies of childhood disabilities for:
- Identification of modifiable risk factors
- Needs assessments → planning of services for children/ families with special needs

Many causes of Developmental Disabilities are:
- Potentially preventable and/or treatable
- But remain common, unrecognized & untreated in resource-poor environments
The World Health Organization (WHO) estimates that, worldwide, 15%-20% of children have disabilities; 85% of which are in developing countries.
Some forms of developmental disabilities appear to be more common in low-income countries

Prevalence of MR
- Developed countries: 2 – 5/1000
- Developing countries (variable):
  - 2.9/1000 (Beijing)
  - 22/1000 (Lahore)

Prevalence of epilepsy: 5 to 8 persons/1000
- Prevalence in developing countries (tropical countries) twice that in developed world (Some studies)
- Possible regional factors: ↑ prevalence of neurocysticercosis, Japanese encephalitis & head injuries
Prevalence of Autism
Developed versus Developing countries

- Developed countries - 4-5 Per 1000
- Developing countries - 1-6 Per 1000
- Autism is more prevalent in countries where nuclear rather than extended family is predominant
- A low incidence of autism is reported in many Latin American countries and in lower income countries such as Kenya, India & Hungary.
- In India, the prevalence of Autism is 1-6 per 1000 - An estimate of 2 million Autistic people.
Disability in India (All age groups)

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

Census 2001

- Vision: 48%
- Speech: 8%
- Hearing: 6%
- Movement: 28%
- Mental: 10%

Disabilities
Disability in India (All age groups)

Prevalence rate: 1.77%: 18.49 million disabled persons

NSSO 2002

Disabilities

<table>
<thead>
<tr>
<th>Disability</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low Vision</td>
<td>4.39%</td>
</tr>
<tr>
<td>Blindness</td>
<td>10.88%</td>
</tr>
<tr>
<td>Speech</td>
<td>11.65%</td>
</tr>
<tr>
<td>Hearing</td>
<td>16.55%</td>
</tr>
<tr>
<td>Locomotor</td>
<td>57.5%</td>
</tr>
<tr>
<td>M R</td>
<td>5.37%</td>
</tr>
<tr>
<td>Mentally Ill</td>
<td>5.95%</td>
</tr>
</tbody>
</table>
Childhood Disability in India (upto 5 yrs)

Developmental delay / disability: 2.5%

Nair et al: An Anganwadi based survey 1998

Disabilities

- Visual & Hearing: 20.3%
- Speech & Language: 29.8%
- Cerebral Palsy: 12.3%
- Orthopedic Deformities: 26.1%
- Mental Retardation & Related: 8.1%
- Others: 3.8%

Percentage
Methodological issues in epidemiology of disability

■ **Critical issues:**
  ■ Case definition: Absence of specific biologic markers for DD’s; it varies widely across settings
  ■ Level of disability at which screening should occur
  ■ Methods of case ascertainment
  ■ Sources of data
Limitations of Indian data/ Data in developing countries

- Available primary methods are:
  1. Informal community identification; underestimates (stigma, parents unaware, less severe missed)
  2. Clinic based data (Inadequate, no records kept for long)
  3. Administrative ascertainment (Insertion of items in census/ surveys & use of key informants not reliable)
  4. Case registry (hardly existent)
  5. Direct population survey (most productive household survey in developing countries)
Two-Phase Methodology for Population-Based Studies of Childhood Disability

- Phase 1: Screening: Simple and efficient screening tools are limited
- Phase 2: Comprehensive Assessment: Determines what type(s) of disabilities are present; information on severity, causes, impairment, disability, participation, rehabilitation needs, Referral to services

Limitations of Two-Phase Design:
- Phase-two assessments are expensive, need professional resources
- Analysis of data is difficult, requires advanced computer programs & training
Characteristics of 10 Questions Screen

- **Sensitivity:**
  - >80% for serious cognitive, motor & seizure disabilities
  - Lower for vision/ hearing disabilities not previously identified; as low as 4% for mild vision disability
  - Lower for mild disabilities
  - Lower for disorders of communication (Autistic spectrum disorders); ADHD; learning disabilities and multiple disabilities

- **Specificity:**
  - > 85% for serious disabilities: children without disabilities screened negative

- **Positive Predictive Value:**
  - < 30%: Need for second phase to confirm disability
Objectives: Phase I

1. To formulate a “Neuro-developmental disability screening tool” (NDST) for community-based screening of children aged 2-9 years in India

2. To develop, “Consensus Clinical Criteria” (CCC) for the diagnosis of specific neuro-developmental disorders

3. To validate the NDST using Consensus Clinical Criteria (CCC)
4. To estimate the prevalence of neuro-developmental disabilities amongst children aged 2–9 years using two-phase survey method [Phase 1: NDST, Phase 2: CCC]

5. To identify the clinical spectrum of neuro-developmental disabilities in the study population

6. To identify potentially modifiable known risk factors for neuro-developmental disabilities
Constitution of local Technical Advisory Group (TAG)/National TAG/International TAG

Experts from India & abroad: Pediatric Neurologists, pediatricians, psychologists, social scientists, educators & rehabilitation specialists

Development of the NDST Draft by Meetings/Teleconference

3 day workshop in Delhi

Review of NDST draft by TAG (meetings/teleconference)
Indian & International experts communicated by meetings & teleconference

Three-day workshop in Delhi

Based on available Case Definitions and National and International criteria; peer-reviewed by 25 pediatricians/pediatric neurologists from India/abroad in addition to review by eminent social scientists/educators/rehabilitation specialists & psychologists
Proposed activities over the next 3 months

- Validation in four different strata: rural, urban, hilly areas and tribal areas; 1000/stratum
- NDST Likert scale & dichotomous will be applied by Research Assistants and Physicians
- Order effect will be taken care of by making 2 separate random sequencing in which NDST will be applied by Research Assistants and Physicians
- All children will be evaluated by Pediatrician with application of CCC
- Sensitivity, specificity, construct validity & reliability will be determined
- A National Expert Committee (NEC) will evaluate a randomly selected 3% of the case record forms
Estimation of Neurodevelopmental Disability prevalence and risk factors:

**Study design:** Population based cluster survey using the Probability Proportionate to Size (PPS) technique

- The whole country will be divided into five zones, taking geographic and socio cultural factors into consideration
- 3 districts will be identified randomly in each zone. These 3 districts will make zonal sampling frame
Phase I

- Qualitative research methods
- In-depth interviews and FGDs with key informants
- Identification of themes and sub-domains

Phase II

- Quantification of risk factors during cluster survey
Expected outcome

- A culture-sensitive and valid Neurodevelopmental Disability screening tool covering all 10 Neurodevelopmental disabilities.
- "Consensus Clinical Criteria" for classifying Neuro-Developmental Disability
- Prevalence of Neuro-Developmental Disability in Children in India (including Autism/ motor/sensory/cognition)
- Prevalence of potentially modifiable risk factors according to region

Such a broad based NDD screening tool will have applicability in India and other LMICs
Framework for a National Program for Screening of NDD & Intervention

Step I
Health Worker

NDST

Step II
PHC Doctor

NDST repeat (to improve specificity)

Step III
District Pediatrician

Clinical Consensus Criteria

Assign specific diagnostic criteria

Intervention

Step IV
Referred to Tertiary Care Hospital

Clinical Consensus Criteria (Condition requiring special investigation)

Assign specific diagnosis

Intervention
Potential Impact of Study

- Strengthening of existing facilities according to prevalent disabilities.
- Provide data to identify the gaps in the need and profile of such facilities across the country.
- Advocacy for an efficient and rational resource allocation.
- Design & execute appropriate intervention programs to prevent/reduce Neuro Developmental Disabilities.