Disability Research in a Developing Country

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Objective

• Demonstrate how research can change the quality of child survival and human lives
Presentation Plan

• Epidemiological Research: Cross Sectional Studies

• Evidence-Based Practice: Prospective Studies

• Public Health issues: Case Studies

• Future directions
Epidemiological Research: Cross-Sectional Studies
Newborn, Infant and Child Mortality Trend and Target in Bangladesh

- U5MR
- IMR
- NMR
Bangladesh: Mortality declining
Disability rising (per 1000)

Bangladesh Health Watch, 2006
Strategies for Estimating the Prevalence of Disabilities in Populations

• Administrative Record Review (schools, clinics, other social services)
• Registries
• Birth Cohort Studies
• Household Censuses, Surveys
• Key Informant Surveys
• Utility approaches (e.g., DALY)

• Two-Stage Prevalence Surveys

Underestimates:
- Underprivileged
- Poor
- ‘Silent’ ‘Covert’
- Girl child
- Very young
- Inadequate info
Two-Stage Design for Home-based Screening followed by Center-based Assessment of Children with Disabilities in Underserved Populations

Screening of All Children

Screened + (<20%)

Clinical Assessment

Disability “True Positive”

No Disability “False Positive”

Screened – (>80%)

Clinical Assessment (10% of screened-)

Disability “False Negative”

No Disability “True Negative”

No Assessment (90% of screened -)

The Ten Questions: piloted in 10 countries; major surveys in Bangladesh, Jamaica and Pakistan. Zaman et al, 1990; Khan and Durkin, 1995; >30 publications. Most used instrument world-wide (Maulik and Darmstadt, Pediatrics, 2007)

Only Stage One done in >30 countries

Disability directly related to Poverty

% screened positive for disability in B'desh

- Bosnia: 7%
- Thailand: 12%
- Bangladesh: 18%
- Cameroon: 23%
- Central African Republic: 31%

Disability directly related to Poverty

Results from the Multiple Indicator Cluster Surveys

Monitoring Child Disability in Developing Countries
Stage Two: Professional Assessment Tools

Bangladesh, Jamaica, Pakistan: doctors, psychologists

MEDICAL ASSESSMENT
- General Developmental Assessment (GDA)

PSYCHOLOGICAL ASSESSMENT
- Psychometric Tests
- Tests of Adaptive Behaviour

DIAGNOSIS
- Consensual Diagnosis
- Impairment, Disability, Handicap (WHO, 2001)
Selected References: *Studies funded by NIH; CDC, USA*

Wealth and full immunisation coverage
(children 12-13 months old)
In Pakistan and south eastern India, less than 25 percent of the households consume iodised salt.
Children with Vitamin A deficiency face a 25 percent higher risk of dying from childhood illnesses.
In 1997, the net enrollment ratio for secondary schooling in South Asia was 41 percent of all girls as against 61 percent of all boys.
Evidence for Cross-Cultural Comparability of the 10 Questions Screen for Childhood Disability: Sensitivity

% of serious disability identified

[Bar chart showing comparison of Bangladesh, Jamaica, and Pakistan for Cognitive, Motor, Seizure, Vision, and Hearing disabilities.]

- Bangladesh
- Jamaica
- Pakistan
Disability Dynamics: Targeting Impairments

World Health Organization, ICF, 2001

Normal

Disease: body structure and function  Reversible

Impairment: temporary activity limitation

Disability: permanent activity limitation: mild, moderate, severe  Irreversible

Handicap (poor social participation)  WHO, 2001
Prevalence of **Impairment** vs. **Disability** in 5 sites in Bangladesh by PHC/CBR services

<table>
<thead>
<tr>
<th>Site</th>
<th>Impairment</th>
<th>Disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dhamrai</td>
<td>10.83</td>
<td>8.55</td>
</tr>
<tr>
<td>Savar</td>
<td>4.07</td>
<td>23.44</td>
</tr>
<tr>
<td>K'ganj</td>
<td>32.77</td>
<td>31.4</td>
</tr>
<tr>
<td>N'shingdi</td>
<td>30.21</td>
<td>26.03</td>
</tr>
<tr>
<td>Faridpur</td>
<td>49.18</td>
<td>23.14</td>
</tr>
</tbody>
</table>

**Legend:**
- Good CBR; Good PHC
- Poor CBR; Good PHC
- Poor CBR; Poor PHC
- Very poor PHC
Limitations of TQ-based two stage survey

1. Does **not** address ‘impairments’, focuses on ‘serious’ disabilities
2. Does **not** screen <2 year olds
3. Stage Two **requires** multidisciplinary professional teams to assess
4. Stage Two assessment procedures need **standardization**, especially psychometric tools
An Alternative Single Professional Approach: assessment for 2-9 year olds field tested, awaiting publication

Validation of Rapid Neurodevelopmental Assessment Instrument for Under-Two-Year-Old Children in Bangladesh

Authors: Naila Zaman Khan, MD, PhD, Humaira Muslima, MBBS, DCM, Diara Begum, MSc, Asma Begum Shilpi, MSc, Salina Akhtar, HSC, Khaleda Bilkins, MSc, Nasreen Begum, MBBS, MPH, Monowara Parveen, MSc, Shamim Ferdous, MBBS, DCH, Romella Morshed, MSc, Manaash Batra, MD, and Gary L. Darmstadt, MD, MS

What's known on this subject: High prevalence of risk factors places large numbers of children at risk for NDIs and disabilities, and there is a lack of standardized, structured tools or trained professionals to recognize NDIs in children <2 years of age in low- and middle-income countries.

Khan, Muslima, Darmstadt et al, Pediatrics, 2010
Multidisciplinary professionals (physicians, therapists, special teachers) from Bangladesh, Bhutan and Australia (Fiji) attending the RNDA workshop, Dhaka, September, 2010

Evidence-Based Practice: Prospective Studies
Incidence by Diagnosis: CDC, DSH

Data from 4800 children, Child Development Center, Dhaka Shishu Children’s Hospital, 2001
Side effects of phenobarbital and carbamazepine in childhood epilepsy: randomised controlled trial

Selina H Banu, clinical neurophysiologist and paediatric neurologist, Mosharat Jahan, primary care physician trained in childhood epilepsy, Umme Kulsum Koli, child psychologist, Saadie Ferdousi, child psychologist, Neil Neville, Prince of Wales's professor of treatment of epilepsy, Banu and colleagues deserve praise for providing more evidence supporting its use in resource restricted settings.

Treatment of epilepsy in developing countries
Cheap and effective drugs exist but are not accessible to most patients

Of the 35 million people with epilepsy who live in developing countries, around 85% receive no treatment at all. As a consequence, they experience morbidity related to seizures and the psychosocial consequences of stigma and discrimination. Regrettably, most of these people—many of whom are children—could have their seizures completely controlled and they could return to a normal life by taking a single daily dose of a drug that costs less than $3 (£1.50; €2.20) each year. In this week's BMJ, a randomised controlled trial conducted in Bangladesh by Banu and colleagues compares the effects of carbamazepine and phenobarbital on seizure control and behavioural side effects in 108 children with epilepsy.

Assigned to phenobarbital. Drug concentrations were not reported. The two groups were not well balanced for some characteristics: girls were under-represented in the phenobarbital group, a potentially important factor because behavioural problems were more frequent in girls than in boys.

Despite these limitations, the study shows that most children tolerated phenobarbital well and behaviour even improved in many. This supports other findings in similar settings. In a randomised study of 302 children and adults with epilepsy in rural Kenya, side effects were reported more frequently with phenobarbital than with carbamazepine, but the number of patients with side effects did not differ significantly
Advocacy: Pharmaceuticals restarted manufacturing phenobarbitone

SH Banu, trained in GOSH, 1999-2003
How to reach unreached children?

**RCT: Distance Training Packages**

- Pictorial Manuals used as guidelines and reminders for parents
- Manuals for: **Motor, Speech, Cognitive development, ADL**
- Idea from a VSO, UK physiotherapist

**Distance Training Package:**
head control through play activities

- Trained community workers working with mothers in a rural home

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McConachie, Zaman, Khan et al, *J of Peds*, 2000, funded by **DFID, UK**
Functional outcomes for all children followed up for two years

McConachie et al, J of Peds, 2000
Negative findings

1. One third had difficulty in attending sessions due to travel costs, family restrictions, cultural taboos (McConachie et al, CCHD, 2001)

2. Mortality highest among malnourished and tetraplegic group (Khan et al, DMCN, 1998)

3. Mothers became high risk for psychiatric morbidity (Mobarak et al, J Pediatric Psychology, 2001) (Similar finding PTBs FU: Khan et al, CCHD, 2009; funded by SNL)
   - most compliance mothers most at risk
   - ‘burden of caring’ eg. poor sleep, difficulty feeding; behavior problems increased stress
   - stress decreased in ‘no intervention’ group
Seating and Feeding Clinic
for children with Cerebral Palsy

Outcomes: Before & after

Mel Adams, field work in CDC, DSH, obtained PhD from London University, 2008
Adams M, Shilpi AB et al, 2009, submitted to DMCN;
low cost aids, Center for the Rehabilitation of the Paralyzed (CRP): Valerie Taylor
Visual improvement by initial visual functions
(best results in 6-13 month infants: Humaira Muslima et al, 2000)

% of improvement in vision

- 29% with no functional vision
- 42% with some vision
Early intervention for visual impairment
(“Show me what my friends can see”: Dhaka Shishu Hospital, 2001)
Neurodevelopmental Follow Up of **Preterm Infants**: Early Identification, Early Intervention Outcomes

*(Khan NZ, Muslima H, et al, Pediatrics, 2006)*

At 1 month

- Low risk: 6%
- Moderate risk: 39%
- High risk: 55%

At 30 months

- Normal: 32%
- Mild impairment: 45%
- Serious impairment: 23%
Rising maternal stress with increasing numbers of visits in a cohort of preterm infants
(Khan, Muslima, Parvin, Bhattacharya et al, 2007, submitted to J of Pediatrics)

Risk for psychiatric morbidity in mothers
Establishment of Shishu Bikash Kendra (CDCs) in 14 Government Medical College Hospitals

- 2008-2009
- 2009-2010
- 2010-2011
Public Health issues: Case Studies
Deadly lead in city air disabling children

8 times the WHO limit found in blood samples

By Special Correspondent

Blood samples of patients reporting for unusual behaviour at Dhaka Shishu Hospital show presence of lead at least eight times the limit recommended by World Health Organisation (WHO), a doctor said.

It could be just the tip of an iceberg as many more children untested may be at risk, the doctor said. "The tests done at Dhaka University and Bangladesh Atomic Energy Commission showed presence of 93 to over 200 micrograms of lead in the samples," Dr. Naela Khan, a child neurologist, told reporters yesterday.

WHO says that presence of more than 25 micrograms of lead per decilitre of blood is unsafe. If lead goes above 10 micrograms, says the American Centre for Disease Control, it can be dangerous for humans, facing long term problems like disability.

"Initial tests showed 'lead lines' on their bones which prompted us to send the samples to the only laboratory facilities available in the country," she said.

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Media Campaign Against Leaded Petrol
Child Protection: Study of CSA in CWDs

Bangladesh Protibondhi Foundation, 2009

Funded by Save the Children, Sweden-Denmark
Percentage of sexual abuse and types of disabilities:

111/216 (51%) abused or ‘possibility’
## Distribution of age and possibility of sexual abuse and case of sexual abuse

<table>
<thead>
<tr>
<th>Age/Form of Abuse</th>
<th>N (7-10)</th>
<th>%</th>
<th>N (11-14)</th>
<th>%</th>
<th>N (15-18)</th>
<th>%</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Possibility of Sexual Abuse</td>
<td>14</td>
<td>12.61</td>
<td>11</td>
<td>9.90</td>
<td>2</td>
<td>1.80</td>
<td>24.3% (27)</td>
</tr>
<tr>
<td>Sexual Abuse</td>
<td>32</td>
<td>28.28</td>
<td>28</td>
<td>25.22</td>
<td>18</td>
<td>16.21</td>
<td>75.7% (84)</td>
</tr>
<tr>
<td>Total</td>
<td>46</td>
<td>40.89</td>
<td>39</td>
<td>35.12</td>
<td>20</td>
<td>18.01</td>
<td>100% (111)</td>
</tr>
</tbody>
</table>
Future Directions
Changing incidence of neurodevelopmental impairments recorded in the CDC: between 1991-2000 and 2001-2006

Conclusion

- **Epidemiology, clinical audit, evidence-based research** are able to prevent and ameliorate disability.

- **Research and publications** based upon the above are able to provide government with **valid direction** for prevention and care.

- **Changing** scenarios need to be determined, at least once in every decade.

- International donors and researchers need to connect with **national professionals**, to be able to achieve sustainable changes in the public sector.