Regional progress and challenges in Newborn-Birth Defects in South-East Asia Region

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Reduction in NMR has been much slower.
Goal 3- Ensure Healthy Lives and Promote well-being for All at All ages
New Targets: From MDGs to SDGs

MDG 4
Reduce child mortality by two-thirds

MDG 5
Reduce maternal mortality by three-fourths

SDG 3 Ensure Healthy Lives and promote wellbeing for all at all ages

3.1 By 2030, reduce the global maternal mortality ratio to less than 70 per 100,000 live births

3.2 By 2030, end preventable deaths of newborns and children under 5 years of age, with all countries aiming to reduce neonatal mortality to at least as low as 12 per 1,000 live births and under-5 mortality to at least as low as 25 per 1,000 live births
GLOBAL STRATEGY for Women’s, Children’s and Adolescents’ Health

Objectives

1. **SURVIVE**
   End preventable deaths

2. **THRIVE**
   Ensure health and well-being

3. **TRANSFORM**
   Expand enabling environments
Effective interventions

70% of newborn deaths can be prevented by high quality coverage (90%) with available interventions.

80% deaths are related to preterm-low birth weight.

Half of neonatal survival depends on better maternal care.
How many additional neonatal lives can be saved with a very high coverage (~90%) of available interventions: Global

- 71% neonatal deaths
- 33% stillbirths
- 54% maternal deaths
The Challenges

Interventions for MNCH are well known... but

Coverage remains low
Inequality in coverage of health services, South-East Asia Region, 2010–2015

Focusing at childbirth and first week

CARE AT BIRTH, TRIPLE RETURN
Highest impact, Highly cost effective
Benefits women, stillbirths, newborns

3 MILLION LIVES SAVED PER YEAR
Running cost $1.15 per person
Care around childbirth (mother+baby) and care of sick and small babies will give maximum dividends

Source: The Lancet Every Newborn series, paper 3
As child mortality levels decline, causes of mortality shift

Distribution of Causes of Death among Children Under-Five According to Levels on U5MR

Liu et al (2014)
The Lancet
Birth Defects account for 3% to 20% U5MR

Birth Defects, PT births and Birth Asphyxia together account for 35% to 55% of under-5 mortality and share many risk factors.

Risk factors are often associated to many outcomes

Examples of Established or Possible Risk factors

<table>
<thead>
<tr>
<th>Risk factor</th>
<th>Birth Defects</th>
<th>Preterm Birth</th>
<th>IUGR</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family planning &amp; reproductive plan</td>
<td></td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Nutrition pattern</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Non-optimal folic acid / vitamins</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Smoking</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Alcohol use / abuse</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Illicit drugs</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Obesity</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Chronic diseases (e.g.: diabetes)</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Infectious diseases</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Medications</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Working activity</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Psyco-social stressors</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Environment</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
</tbody>
</table>
Linking Newborn Health and Prevention of Birth Defects
Regional Initiatives

- Regional Flagship initiative: Ending preventable maternal, newborn and child mortality with a focus on reducing newborn mortality.
- SEAR-Technical Advisory Group (SEAR-TAG) on Women’s and Children’s Health has been. First Meeting held in Dec 2015
- Regional H6 Summit and Joint Statement: WHO, UNICEF, UNFPA, UNAIDS, UN WOMEN, World Bank
Urges Member States to

(1) raise awareness

(4) increase coverage of effective prevention

(5) develop and strengthen registration and surveillance systems for birth defects

(7) strengthen research and studies on etiology, diagnosis and prevention of major birth defects and to promote international cooperation in combating with them
Birth Defects: Inadequate information

ESTIMATES IN SEAR
MARCH OF DIMES GLOBAL REPORT ON BIRTH DEFECTS (2006)

Birth Defects prevalence / 1000 live births

<table>
<thead>
<tr>
<th>Country</th>
<th>Prevalence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bangladesh</td>
<td>58.6</td>
</tr>
<tr>
<td>Bhutan</td>
<td>58.4</td>
</tr>
<tr>
<td>DPR Korea</td>
<td>54.1</td>
</tr>
<tr>
<td>India</td>
<td>64.3</td>
</tr>
<tr>
<td>Indonesia</td>
<td>59.3</td>
</tr>
<tr>
<td>Maldives</td>
<td>60.6</td>
</tr>
<tr>
<td>Myanmar</td>
<td>58.5</td>
</tr>
<tr>
<td>Nepal</td>
<td>59.9</td>
</tr>
<tr>
<td>Sri Lanka</td>
<td>62.2</td>
</tr>
<tr>
<td>Thailand</td>
<td>59.9</td>
</tr>
<tr>
<td>Timor Leste</td>
<td>60.3</td>
</tr>
</tbody>
</table>
Goal:
Significant reduction of preventable birth defects in the South-East Asia Region to contribute to achievement of MDG4 and beyond.

Targets
Reduce the prevalence of folic acid-preventable neural tube defects by 35%;
Reduce the number of thalassemia births by 50%;
Reduce congenital rubella;
Eliminate congenital syphilis.
National Plans for Birth Defects

• National birth defects focal points in MoH

• National Plans: Nine countries
  – Multi-stakeholders meetings
  – National Plans:
    • Surveillance
    • Primary prevention: Integrated approaches
    • Early diagnosis, management and care

Bangladesh, Bhutan, India, Indonesia, Myanmar, Maldives, Nepal, Sri Lanka, Thailand
Standard protocols for management of birth defects

- Prevention and management of thalassemia
- Prevention and management of Down’s syndrome
- Guidelines for Newborn screening
- Guidelines for early hearing screening
- Management of spina bifida
Communication for Birth Defects

Regional Communication Strategy

Policy Briefs

- Addressing birth defects: Accelerating progress towards the unfinished task of MDG4
- Prevention and control of birth defects in South-East Asia: Strategic Framework, 2013–2017
- Elimination of congenital syphilis
- Fortifying staple food to prevent neural tube defects
- Preventing congenital rubella syndrome (CRS)
Capacity development for Birth Defects Surveillance

CDC- WHO Surveillance Training Package:
  Manual
  Facilitators’ Guide
  Photo Atlas

2 day training package-
Trainers guide and
SOPs for hospital based surveillance

National Trainings:
Bangladesh, India, Indonesia, Nepal, Maldives, Sri Lanka, Thailand
Launched on 1st July 2014
Number of hospital enrolment with NBBD and reporting data from the region
## Prevalence of Birth defects by the countries

<table>
<thead>
<tr>
<th>Details</th>
<th>Bangladesh</th>
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<th>India</th>
<th>Maldives</th>
<th>Myanmar</th>
<th>Nepal</th>
<th>Thailand</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of hospital reported data</td>
<td>15</td>
<td>1</td>
<td>74</td>
<td>1</td>
<td>5</td>
<td>10</td>
<td>13</td>
<td>119</td>
</tr>
<tr>
<td>Total births covered</td>
<td>67,253</td>
<td>5,264</td>
<td>464,274</td>
<td>1,534</td>
<td>39,315</td>
<td>104,818</td>
<td>56,744</td>
<td>739,202</td>
</tr>
<tr>
<td>Total no. of babies with birth defects reported</td>
<td>686</td>
<td>120</td>
<td>4280</td>
<td>42</td>
<td>53</td>
<td>375</td>
<td>324</td>
<td>5880</td>
</tr>
<tr>
<td>Prevalence of Birth defects per 1000 births</td>
<td>10.2</td>
<td>22.8</td>
<td>9.2</td>
<td>27.4</td>
<td>1.3</td>
<td>3.6</td>
<td>5.7</td>
<td>8.0</td>
</tr>
</tbody>
</table>

Indonesia 13 Hospitals collecting data. Sri Lanka to start reporting from 15 hospitals.

1st July 2014 to 30th June 2016
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</tr>
<tr>
<td>Number of birth defects reported</td>
<td>1144</td>
<td>162</td>
<td>5764</td>
<td>76</td>
<td>72</td>
<td>460</td>
<td>366</td>
<td>8044</td>
</tr>
</tbody>
</table>

1st July 2014 to 30th June 2016
Proportion of types of birth defect (n= 8,044)

1st July 2014 to 30th June 2016
Birth prevalence of types of birth defect (n= 8,044)

1st July 2014 to 30th June 2016
Distribution of birth defect by weeks of gestation

1st July 2014 to 30th June 2016
Distribution of birth defect by sex of the baby

1st July 2014 to 30th June 2016

- Neural Tube Defects
- Orofacial Cleft
- Hypospadias
- Talipes Equinovarus
- Reduction Defects Of Limbs
- Abdominal Wall Defects
Types of birth defect and the outcome before discharge from Hospital

1st July 2014 to 30th June 2016

- Neural Tube Defects: 20.9% Died, 43.6% Alive
- Talipes Equinovarus: 7.0% Died, 89.3% Alive
- Orofacial Cleft: 6.7% Died, 89.6% Alive
- Reduction Defects of Limbs: 10.3% Died, 85.1% Alive
- Hypospadias: 2.9% Died, 95.8% Alive
- Abdominal Wall Defects: 19.4% Died, 66.3% Alive

Percentages based on the study period.
Burden of congenital malformations

- Prevalence
- Mortality: neonatal, infant, under-5 years
- Elective terminations (ETOPFA)
- Spontaneous abortions
- Stillbirths
- Survival
- Co-morbidity
- Surgical, medical treatment, hospitalization
- Long term disability
- Quality of life
- Social and emotional impact
- Economic cost

Tip of the iceberg

Mostly invisible
Neural tube defects occurrence
(as percent of total birth defects)

- Per-viable: 44.5%
- Stillbirths: 28.4%
- Live births: 13.0%
• For prevention of Birth Defects we do not need to start from a scratch....

• Member States are already implementing several useful interventions
Outcomes in the absence of interventions

Conception → Continuing pregnancy → Live birth → Disability

Miscarriage → Stillbirth → Death
Pre-pregnancy intervention

Conception

Miscarriage

Termination

Continuing pregnancy

Stillbirth

Live birth

Prenatal diagnosis

Diagnosis and care

Cure

Disability

No care

Death
Interventions that can be integrated into existing programmes

• **Pre-conception care services:**
  – Preventing consanguineous marriages
  – Pre-natal screening for carriers-Thalassemia, sickle cell
  – Preventing pregnancy at advanced maternal age
  – Folic acid fortification/ supplementation:
  – Immunization: Rubella vaccine
  – NCD (diabetes, hypertension and obesity) prevention through healthy lifestyles promotion, screening and treatment

• **Reinforcing and improving antenatal care services:**
  – No medications during first trimester
  – Syphilis screening
  – Prevention of exposure to tobacco and alcohol
  – Prevention and management of diabetes, hypertension and obesity during pregnancy
  – Antenatal screening and prenatal tests for BD

• **Improved perinatal care:**
  – Asphyxia prevention and management
  – Neonatal screening for BD, management and rehabilitation
Fortification Efforts

- **Situation Analysis:** Micronutrient fortification and supplementation
- Indonesia and Nepal - mandatory?
- India- Guidelines on wheat flour fortification, standards
- **Pilot:** To demonstrate feasibility, effectiveness and health impact of wheat flour fortification. (MoH,WHO,CDC,UNICEF,WFP,GAIN,FFI,MI)
Newborn-Birth Defects in SEAR
What has been achieved......

• National commitments in the form of National Newborn Action plans and National Birth defects plans.

• Interventions being incorporated / strengthen in MNCAH, Immunizations and HIV/STIs programmes

• Surveillance started in hospitals - focus on birth defects, newborns, still births and pre-viable births.

• Increased high level advocacy and commitments-RD flagship and WHA resolution.

• Capacity building: Regional-National networks and at birth quality of maternal and newborn care

• Focus on Pre-conception care
NETWORK–CONNECT

SOUTH EAST ASIAN REGIONAL NETWORK FOR NEWBORN & BIRTH DEFECTS

highlights in August 2013 (1. EBlast)

WHO Collaborating Centre for Training And Research in Newborn Care

WHO Collaborating Centre for Training in Clinical Laboratory Genetics in Developing Countries

Department of Pediatrics, All India Institute of Medical Sciences, New Delhi, India

Prevent Birth Defects
Improve Newborn Survival
Ensure Quality of Life and Dignity

Thank You
Integrating prevention interventions in existing programmes

- **Nutrition**: Micronutrient supplementation and fortification
- **Preconception-periconception care**: Folic Acid supplementation/fortification, Health education, screening for risks and carriers - Thalassemia, sickle cell disease etc
- **Antenatal care**: Gestational diabetes, obesity, medications
- **Immunization**: Rubella vaccine for CRS prevention
- **Syphilis screening** and management for eliminating congenital syphilis
- **Pre-conception care package-adolescents-Healthy Transition package**
Birth prevalence of types of birth defect by country (n= 8,044)

Per 10,000 births

1st July 2014 to 30th June 2016

- Neural Tube Defects
- Orofacial Cleft
- Hypospadias
- Talipes Equinovarus
- Reduction Defects Of Limbs
- Abdominal Wall Defects
Distribution of birth defect by age of the mother from 1st July 2014 to 30th June 2016.