Why this conference on birth defects in India ?

Pune Public Health Conference 2013 on reproductive and child health

Pregnancy loss, birth defects and genetic disorders :
Epidemiology, social costs, health systems needs

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Children with birth defects are visible in India------- children with disability, their struggle for survival, and the trauma of their parents as there is no structured health programme to help these families

Congenital anomalies

Neural tube defects
Congenital heart defects
Limb deformities

http://www.guardian.co.uk

Chromosomal abnormalities

Down syndrome

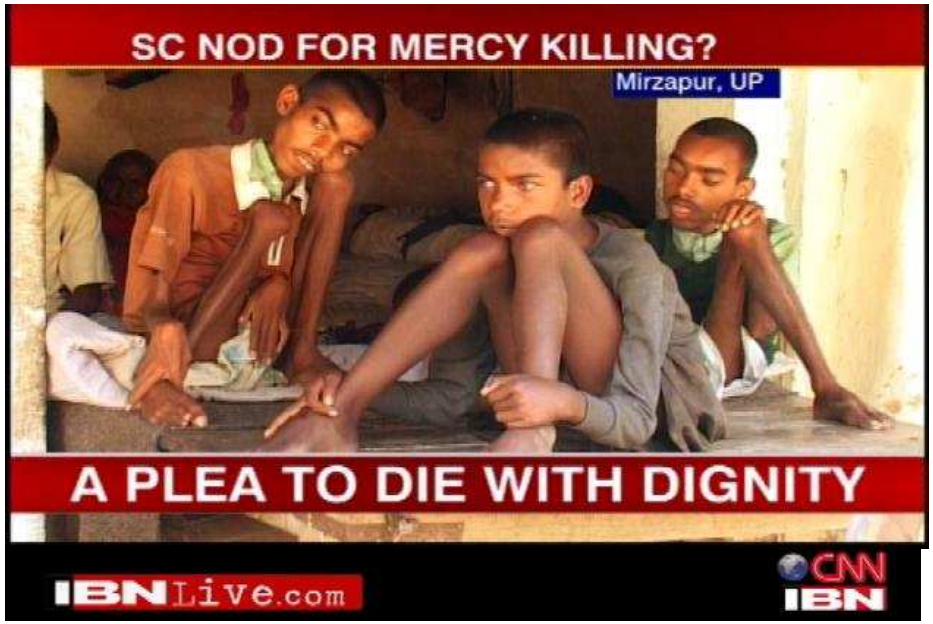
http://www.worlddownsyndromeday.org

Single gene disorders

Thalassemia, sickle cell anemia, bleeding disorders, muscular dystrophy

Birth defects are also responsible for pregnancy loss, early neonatal deaths

Birth defects are so traumatic that parents have been known to request for euthanasia



http://ibnlive.in.com/news

http://www.dnis.org/news.php

The impact of birth defects is most severe on the poorest strata of society

NOTES

1 Bihar parents seek mercy killing for two sons, NDTV Indo-Asian News Service, 9 March 2011; "Will India Allow These Children To Die? *The Times of India*, 22 August 2009; "Muscular Dystrophy Patient Seeks Mercy Killing in AP", *The Hindu*, 22 June 2008; "Tamil Nadu Carpenter Seeks Euthanasia for Ailing Son", PTI, 17 February 2006; "Please Let My Son Die", *Mumbai Mirror*, 29 December 2005; "Euthanasia Seeker Loses Death", PTI, 17 December 2004.

The quality of life of children and parents are extremely poor

- Birth defects are incurable conditions afflicting children, and those who survive till adulthood. Examples are Down syndrome, thalassemia, neural tube defects
- They cause physical and mental disability, or a chronic medical condition, resulting in enormous suffering
- There are no government health services for patients who remain poorly treated, enhancing the suffering
- Parents experience catastrophic, out of pocket, expenditure, survive with the challenge of rearing a child with a chronic condition without support services
- No psychosocial support programme for parents
- No education programme for caregivers
- Medical professionals have no point to refer patients for psycho-social support and education

Birth defects cause pregnancy loss, early neonatal mortality---- their impact on RCH indicators is unknown in India

Can birth defects be an invisible public health problem in India ?

Birth defects affect 2-3% of births. If there were 27 million births in 2010, **800 000 pregnancies should have been affected in India**

Birth defects have been studied by clinicians and geneticists, but very few studies have used a health systems approach with the goal of collecting epidemiological and public health data to develop a programme to prevent these conditions and provide best available care to patients and families

Estimates of the number of affected pregnancies in India

Condition	Total birth prevalence	Estimate of affected births (number of births 27 165 000)
Congenital Heart Disease	5.15/1000 births	139 900
Congenital Hypothyroidism	0.25/1000 births	6791
Down's Syndrome	1.36/1000 births	36 944
Glucose-6-phosphate dehydrogenase deficiency	0.63/1000 births	17 114
Neural Tube Defects	4.09/1000 births	111 105
Orofacial Clefts	1.73/1000 births	46 995
Rhesus D Haemolytic Disease of the Newborn	0.98/1000 births	26 622
Sickle Cell Disease	1.02/1000 births	27 708
Thalassemias	0.23/1000 births	6248

These nine conditions contribute to estimated **419 427** births (**1.5**% of total live births in India)

No research to validate this data

Why are birth defects not considered a public health problem ?

Argument	However…….
Birth defects are rare	India has the largest global number of births, and therefore the absolute numbers of affected are likely to be the largest in this country
These conditions have a genetic (non-modifiable) etiology ---there are larger problems that can be prevented using low cost , population based methods	Preconception care can not only reduce birth defects, but can also reduce the complications of pregnancy and improve birth outcome, thereby improving RCH indicators
Interventions are too cost intensive, will not yield public health benefits	Preconception services are low cost and can be delivered at primary care. With rapidly reducing IMR, it may be time to consider genetic services in public health services
Limited to individuals and families, they do not have the potential for reaching epidemic proportions in the population, ey are not easy to prevent and control	Preconception care is eminently feasible, public-private partnership model for approaching affected parents has to be investigated

A recent global focus points to the feasibility of birth defects prevention in developing countries , focus on preconception interventions and antenatal care

The World Health Assembly has acknowledged that initiatives should be launched in developing countries to prevent birth defects

World Health Organization

SIXTY-THIRD WORLD HEALTH ASSEMBLY A63/10
Provisional agenda item 11.7 1 April 2010

Birth defects

The WHO-South East Asia Regional Office has developed a broad framework for the prevention and control of birth defects in the SEAR countries

Prevention and Control of Birth in South-East Asia, Report of Regional Programme Managers's Meeting, Bangkok, Thailand, 20-22 March 2012'

[PDM 4.5 MB]

Capacity building for birth defects surveillance in South-East Asia, Report of the Regional Workshop on birth defects surveillance, Colombo, Sri Lanka, 10-13 April 2012

[PDF 6.3 MB]

Improving neonatal and child health and development in South-East Asia , Rep meeting of South-East Asia Programme Managers, Kathmandu, N

Low cost, population based methods for prevention of some types of birth defects also reduce the risk of pregnancy complication

Risk factor	Prevention
Micronutrient deficiency : folate, iodine, iron	Balanced diet, supplements
Environmental exposures : pollutants like pesticides, fertilizers, household chemicals, "pest control activities"	Avoiding toxic exposures
Infectious illness such as syphilis, rubella, TORCH infections	Treatment of existing infectious illness, rubella immunization wherever possible
Non-infectious illness eg insulin-dependent diabetes mellitus	Diagnosis, glycemic control and awareness of risks associated with pregnancy
Life-style factors such as over the counter non-prescription medication, tobacco and alcohol use	Healthy lifestyle and practices, awareness about the need to avoid use of self-medication
Physical agents such as exposure to radiation	Avoiding physical radiation
Family history and consanguineous marriages	Avoiding consanguineous marriages, informing doctor if there is a family history of genetic disorder
Advanced age at pregnancy	Access to family planning services

Prevention services (genetic counseling) is not available through public health services, creating a health systems vacuum where there is neither prevention or treatment

Very little data on the burden of these conditions, trends, quality of life of patients, models for offering genetic counseling

The biotechnological competencies of the nation have not been translated into genetic services through the public health system

The “crack in the continuum of RCH care”– lack of preconception care

Prconception care

✓Pre-conception micronutrient supplementation

✓Enhancing awareness on teratogenic risk factors

✓Referral for families with history of hereditary disorders

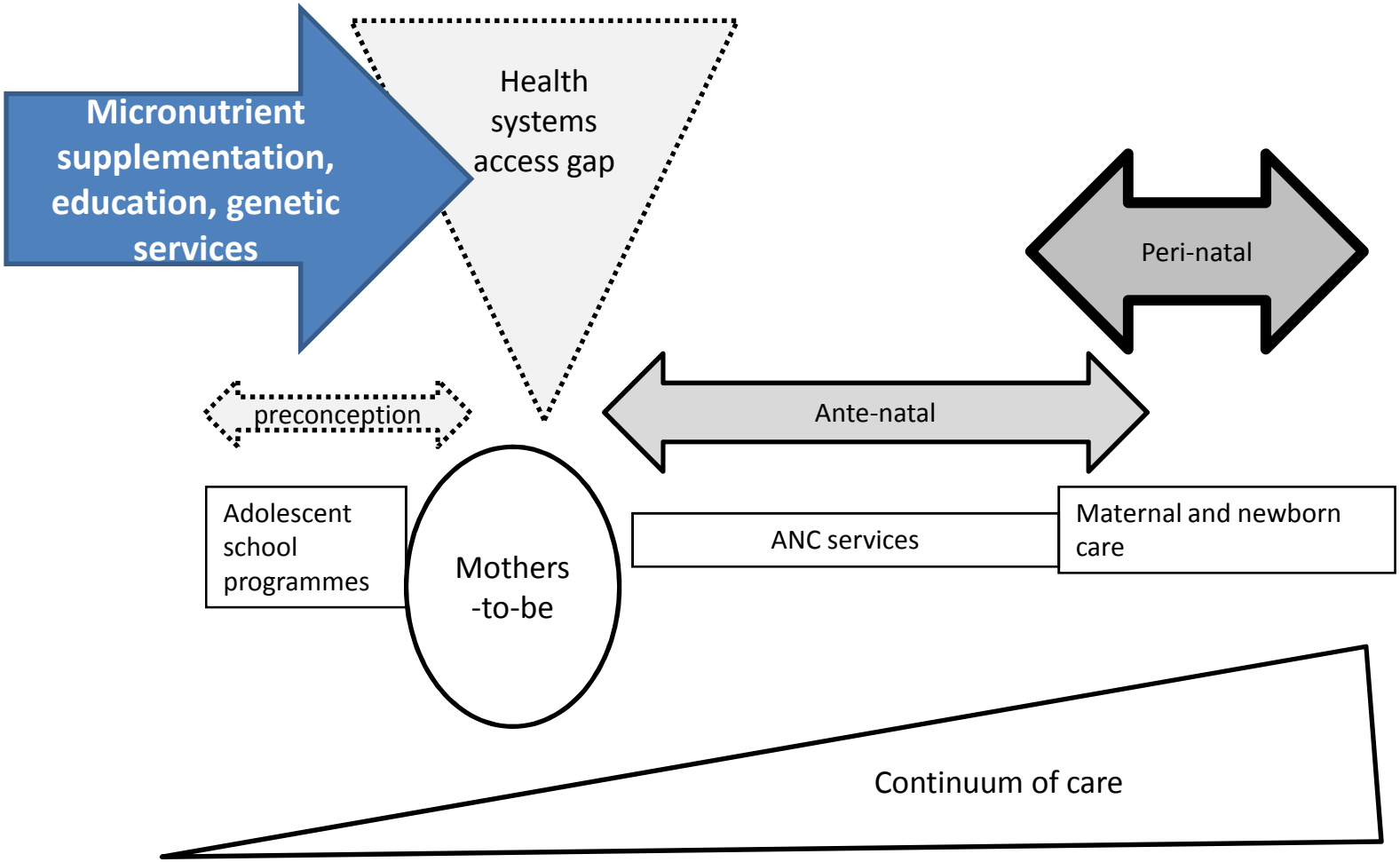
✓Provision of appropriate services

Consanguinity, genetic risk factors

Maternal illnesses

Micronutrient deficiencies

Birth defects prevention , initiating through pre-conception services reduces the complications of pregnancy and contributes to overall improvement of maternal and child health outcomes



The goal of this Conference--- a birth defects research agenda to characterize these conditions using a health systems approach

- ✓ To review the available data on the burden, public health impact and social costs of birth defects in India,
- ✓ To identify knowledge gaps and define key areas for research on birth defects in India;
- ✓ To identify a package of preconception services that can be used to prevent birth defects;
- ✓ To explore the health systems opportunities and gaps to address genetic disorders in India including a mechanism for establishment of genetic services in the public health system
- ✓ To suggest a national framework for services for the prevention of birth defects within the Reproductive and Child Health programme

Components of the birth defects research agenda

I. Epidemiology

- What is the burden of birth defects in India ?
- What are the trends in number of cases in India?
- Do birth defects impact public health indicators ?

II Risk factor prevalence

What is the prevalence of risk factors amongst women of reproductive age, adolescent girls ?

- Tobacco use, alcohol
- Micronutrient deficiencies
- Pesticide or other exposures
- Maternal illness
- Prescription drug use or self-medication during pregnancy
- Use of AYUSH medicines
- Prevalence of psycho-social stressors like work load, abuse, poverty during pregnancy ?
- Genetic predisposition ?

Components of the birth defects research agenda

III Health services

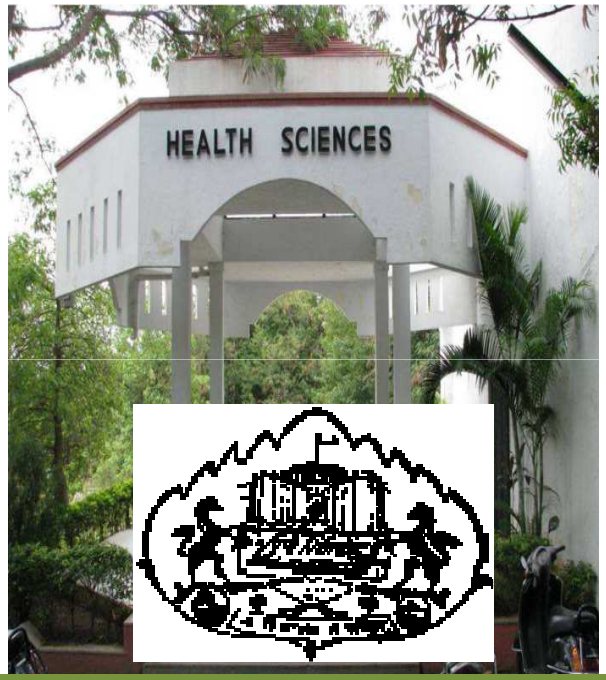
- ✓What should be the components of a birth defects prevention programme in India ?
- ✓Can birth defects prevention activities be implemented through a package of peri-conception services in the RCH programme?
- ✓How can genetic services be introduced in reproductive and child health services ?
- ✓What are the ethical and regulatory guidelines that will be required ?

IV. Patients, parents and families

- ✓What is the approach for best available care for patients ?
- ✓What is the quality of life of affected patients and families ?
- ✓What are the needs of such families?
- ✓Can psycho-social support services be provided to families through health services ?

Please help us in constructing a birth defects research agenda , which may be developed into a future programme for the prevention of birth defects in India

Translating knowledge, making science work



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11th-12th February, 2013

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