Preventing Birth Defects in India

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Evidences indicate that India has the highest number of children with birth defects. The lack of public health support for treatment often means lifelong suffering. Many of the tools to prevent birth defects are inherent in the existing reproductive and child health programme. With some additions, a prevention programme could be initiated in order to address this invisible public health problem.

Birth defects are childhood disorders of such severity that there are media reports of parents appealing for euthanasia to end the suffering of the afflicted child. Birth defects present as congenital anomalies such as when children are born with deformed or missing limbs, cleft palate, congenital heart defects or paralysis. Some of these conditions can be surgically corrected provided parents have the economic ability to pay for the treatment. Other birth defects arise due to chromosomal abnormalities. Children born with Down syndrome are mentally challenged and require special care throughout life. Birth defects caused by single gene disorders, such as haemophilia, thalassemia or sickle cell anaemia cause extreme pain and suffering. The affected children require expensive and specialised treatment such as repeated blood transfusions for thalassemics or repeated infusions of clotting factor concentrate for boys with haemophilia. While thalassemic children receive free transfusions, iron chelation therapy is unavailable at government hospitals. These children die by the second decade, enduring lifelong suffering. Without public health support for treatment, the families experience significant out of pocket expenditure whilst children receive suboptimal treatment (Disease Control Priorities Project 2008).

Estimates indicate that globally, India has the largest number of affected children (Christianson et al 2006). This article presents the argument that a birth defects prevention programme is needed to address this invisible public health problem in India. It points out that many low cost interventions for prevention of birth defects are existent in the Reproductive and Child Health (RCH) programme of the Government of India (Government of India 2005). These interventions can be the starting point for mobilising an Indian birth defects prevention programme to address the issue of “dying and disabled children” (Christianson et al 2006).

There is very little population-based research on birth defects in India. A global estimate suggests that every year around 1.6 lakh children are born with birth defects in this country (Christianson et al 2006). This number is the highest globally, being one and a half times more than that of China, which has the second highest global burden of children with birth defects. Birth defects have been ignored by public health services as they are considered to be rare conditions. The high estimate of children born with birth defects is however not unexpected, as India has the highest birth cohort as well as a high birth rate of 20.97 births per 1,000 population (Census of India 2011).

Prevention Strategies

Birth defects have a significant genetic component which makes these conditions incurable (Disease Control Priorities Project 2008). The genetic component gives the perception that birth defects prevention involves expensive medical genetics services which are too resource-intensive for public health services of Low Income Countries (LICs) (Christianson and Modell 2004). Low cost preventive interventions for birth defects are however available and these form a routine component of preconception pregnancy care. Congenital anomalies, for example, can be prevented by sensitising adolescent girls and pregnant women on five broad groups of teratogenic factors, that is, factors associated with the risk of birth defects (Christianson et al 2006). These factors include the need to treat infections such as syphilis, the need for rubella immunisation, the need to ensure proper management of diabetes and epilepsy during pregnancy, and appropriate intake of micronutrients such as iodine or folic acid throughout a balanced diet. Other factors include prevention of toxic chemical exposures, such as fertilisers or pesticides during pregnancy, prevention of exposure to physical agents like x-rays during pregnancy and avoiding non-prescribed medicines, recreational drugs, tobacco, and alcohol during pregnancy. These interventions are feasible through the existing RCH and Adolescent Reproductive and Sexual Health (ARSH) programmes under the National Rural Health Mission (NRHM). The risk of

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children being born with chromosomal abnormalities increases with increased parental age. Effective family planning services can reduce the risk of these conditions. Many of these strategies are already existent within the RCH programme as a part of continuum of care for ensuring a healthy pregnancy outcome. Birth defect prevention is however not one of the stated goals of the RCH programme.

Prevention Activities

Figure 1 shows the inputs required at different levels of the health system to prevent birth defects. A major part of the low cost prevention activities can be conducted at the level of the primary health centres (PHCs) and sub-centres and will require minimum resource investment. Many of these activities are already a component of antenatal services, albeit without the stated goal of preventing birth defects. Secondary level services will require resource investment. For example, pregnant women above the age of 35 years presenting at PHCs will need to be referred to district hospitals for amniocentesis in order to test for chromosomal anomalies. Genetic counselling will be required for parents reporting family history of a genetic disorder, such as sickle cell anaemia in tribal areas.

Research Inputs and Public Health Benefits

Research is needed to operationalise the birth defects prevention programme, initiating with an estimate of the number of affected births. Birth defect rates are computed through population-based registries. Integral to the registry is the investigation of each birth defect so that toxic exposures (like Endosulfan) can be identified and the population can be protected from the exposure. Research is needed to develop indicators for monitoring the impact of birth defects prevention activities. Health systems research is needed to identify routes by which patients can be referred from public health facilities to secondary and tertiary level of care. Finally, research is needed to determine the cost of providing these services and the benefits that birth defects prevention can provide to public health services. As birth defects account for 7% of neonatal mortality (Lawn et al 2005) prevention programmes are likely to reduce neonatal mortality. The urgency of preventing birth defects in LICs is highlighted by resolution A63/10 of the 63rd World Health Assembly, which recommended that these countries should introduce birth defect prevention strategies in order to achieve Millennium Development Goal 4 which aims at reduction of child mortality in LICs (World Health Organisation 2010). Beyond this, the demographic indicators of India suggest that birth defects may represent an invisible and unaddressed public health problem, taking a severe toll on children and their family members.

References


Notes


2. For example, the Birth Defects Registry of India hosted by the Poelaert Care Research Foundation http://www.fcrf.org.in/brdi_abus.asp; The Federation of Obstetric and Gynaecological Society Birth Defect Registry http://www.fogsli.org/birth_defect_registry.html. These registries provide information on the type of birth defects, they are unable to provide data on the rate of affected births since there may be considerable duplication of reporting amongst these registries.