

Abstract Title: The Socio-political implications of New- born screening programme in India

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Abstract: Newborn screening (NBS) is one of the top ten public health programs in the world that provides preventive healthcare just after birth for disorders that can cause severe illness or death unless detected and treated early.

Newborn screening is not mandatory in India. Pilot studies in India projected a high prevalence of inborn errors of metabolism indicating the need for NBS. To establish NBS in a highly populous country, it should be an exclusive program with an elaborate infrastructure. Until recently, Ministry of health in India did not consider NBS a priority like immunization as a result NBS has not reached the common man yet. The main roadblock is absence of political will and lack of awareness and high cost of testing. The Ministry of Health & Family Welfare, Government of India, launched the Rashtriya Bal Swasthya Karyakram (RBSK), to implement Child Health Screening and early Intervention Services. RBSK is aimed to screen children from 0-18years for the 4 Ds-Defects at birth, Diseases, Deficiencies and Development delays including disabilities. The 1st D – Defects at birth does not specify the inclusion of NBS. Also it does not specify whether the cost of testing is covered. This requires clarification and if allowed, Nationwide NBS can be implemented just like immunization.

Government's role is of utmost importance to implement a nationwide screening. Since NBS should be a national policy, policy development require individuals with sufficient technical knowledge and experience. Legislators, advocacy groups, and key opinion leaders play an important role in helping to raise awareness of the need for newborn screening. NBS is not a simple test, it's a program. Hence absence of policies, quality control, and absence of an authorized body for accreditation of neonatal screening tests in India is creating both negative and positive impact on NBS. False positives are often reported creating anxiety, and fear among the families. No standard protocol is followed while reporting positive results. India Newborn Action Plan (INAP) was launched in 2014 to make concerted efforts towards attainment of the goals of "Single Digit Neonatal Mortality Rate" and "Single Digit Still-birth Rate" by 2030. RBSK covers 30 common health conditions including screening, confirmation and management. These conditions were selected based not only on the magnitude of the problem, but also the critical role they play in the development of the child in their formative years especially their cognitive development. In spite of these programs, NBS for preventable causes of intellectual disability and mortality is yet to begin. Under the "India Newborn Action Plan" launched by the Ministry of health and family welfare, NBS in India is a right step in reducing preventable newborn deaths and disabilities by introducing universal newborn screening

Area of expertise: Clinical Genetics & Pediatrics