

An assessment of the RBSK program's effectiveness in screening for disabilities and developmental delays among children aged 0 – 6 years in the North – Eastern state of Tripura

INTRODUCTION

The *World Medical Assembly* (WMA) declaration of Ottawa on Child health (1998) states that “to reach their potential, children need to grow up in an environment where they can thrive – spiritually, emotionally, mentally, physically and intellectually. That place must be characterized by four fundamental elements: A healthy, safe and sustainable physical and emotional environment; the opportunity for optimal growth and development; adequate health services for healthy child development; and monitoring and research for evidence-based continual improvement into the future” [1]. This declaration applies to children in the age group 0 – 18 years all over the world regardless of their race, age, ethnicity, nationality, political affiliation, creed, language, gender, sex, disease or disability, physical ability, mental ability, sexual orientation, cultural history, life experience or the socioeconomic status of the child or her/his parents or legal guardian. More recently the motto of the Global Strategy for Women's, Children's, and Adolescents' Health (2016-2030), "Survive, Thrive, Transform," emphasizes the importance of ensuring that every child not only survives beyond the age of five but also grows up in environments that support their health, well-being, and full developmental potential [2]. The 2030 Sustainable Development Goal 3 makes it binding upon the signatory states to “Ensure healthy lives and promote well-being for all at all ages” [3]. The goals 3.1 and 3.2 mandates countries to reduce global MMR to less than 70 per 100,000 live births and NMR and U5MR to 12 per 1000 live births and 25 per 1000 live births respectively. Furthermore goal 4.2 calls for individual country action so as to “By 2030, ensure that all girls and boys have access to quality early childhood development, care and pre-primary education so that they are ready for primary education” [4].

India's alignment with the global commitment to promote, support and protect Early Childhood Development (ECD) led to the launching of the Rashtriya Bal Swasthya Karyakram (RBSK) in 2013. This program led by the Ministry of Health and Family Welfare (MoHFW), is also linked to the Ministries of Women and Child Development, Human Resource and Development and Social Justice and Empowerment, as well as the Department of Empowerment of Persons with Disabilities. Administered by the National Health Mission (NHM), the RBSK program was designed with the goal of providing free universal child health screening and facilitating access to early intervention services nationwide. The program's philosophy is centered on transitioning every child from mere 'survival' to 'healthy survival,' ensuring they have access to high-quality healthcare that is grounded in scientific evidence and equitable principles.

Initially, the objectives of the RBSK program encompassed the screening, early detection, and trans-disciplinary management of chronic health issues such as Birth Defects, Diseases, Deficiencies, and Developmental delays (referred to as the 4 D's), along with some optional conditions. At its inception, the program targeted 30 specific conditions. Recently, seven new health conditions have been included: defects like microcephaly and macrocephaly, deficiencies such as vitamin B complex deficiency and

severe stunting, and diseases like childhood leprosy, childhood tuberculosis, and childhood extra-pulmonary tuberculosis. These conditions share common traits in that they are frequently observed in children, and if left untreated, they can result in mortality or adverse developmental outcomes. Early detection, along with timely and appropriate intervention, not only enhances cognitive abilities but also prevents the progression to acute emergencies or the development of permanent disabilities. It is envisioned that if RBSK is successfully implemented, it will minimize health care visits and hospitalization, reduce 'out of pocket' expenditure, and decrease school and work absenteeism, for the family.

RBSK aims at screening children from birth to 18 years, beneficiaries being children born at home or in public health facilities, pre-school children belonging to rural areas/urban slums, and children enrolled in Government or Government aided schools. Facility born children are screened by health personnel within 48 hours of birth. All children are evaluated within 6 weeks of birth under the Home-Based New-born Care package. Thereafter evaluations are made between 3rd and 15th months (on the 3rd, 6th, 9th, 12th and 15th months) under the Home Based Care For Young Children Programme. Those identified with birth defects are integrated with the Janani Shishu Suraksha Karyakaram (JSSK) for further management. Pre-school (6 weeks to 6 years) and school aged children (6 to 18 years) are screened by Mobile Health Teams (MHT) at Anganwadi centers (AWC) twice a year, and at schools annually.

The Mobile Health Team (MHT) consists of two qualified AYUSH (Ayurveda, Yoga and Naturopathy, Unani, Siddha, and Homeopathy) doctors, an Auxiliary Nurse-Midwife (ANM) or Staff Nurse, and a pharmacist who also manages data. This setup optimizes the use of local healthcare providers, particularly in regions with a shortage of allopathic doctors.

The RBSK program further ensures the establishment of a District Early Intervention Centre (DEIC) (for 0-6-year-old children with developmental delay/ disability) that has physical and functional linkages with a SNCU (to cover all discharged high-risk new-borns), and paediatric facility (for birth defects, diseases and deficiencies). Its purpose is to deliver free, evidence-based, transdisciplinary evaluative (clinical, dental, psychometric, hearing and visual assessment and basic laboratory investigations) and intervention services (medical, dental, physiotherapy, occupational therapy, sensory integration, special education, speech therapy, visual stimulation, nutritional rehabilitation, etc). Older children are managed in health facilities, with the DEIC acting as a linkage point.

Therefore the success of the RBSK program is dependent on the effective functioning of its screening and referral services. Keeping these complexities in mind the present study has been designed to look into the gaps in screening (especially in the 0 – 6 years age group) and understand the causes of hesitancy amongst caregivers to avail themselves of screening services as well as the reasons for non compliance post referral. The larger purpose of this study is to comment on the model of the RBSK program and acknowledge the best practices as well as the challenges and barriers affecting the program from reaching its full potential.

LITERATURE REVIEW

Numerous studies and evaluations have assessed the impact of RBSK on child health outcomes. Research indicates that RBSK has improved early detection rates for conditions like birth defects, developmental delays, nutritional deficiencies, and infectious diseases. It has also increased access to healthcare services among underserved populations, leading to better health outcomes and reduced mortality rates among children. However according to relevant literature present on the program it can be substantiated that the parents had been mostly aware of the health problems of their children even before the screening by the MHT but they remained hesitant to take their children to the screening facilities – either because (i) they failed to realize the severity of the problem (ii) they could not accept that their child had an “abnormality” (iii) they felt that the problem will get better with time (iv) they did not receive proper guidance (iv) they did not have the time/resources.

Studies further show that the number of defect detection is far more in the 0 to 6 years age group than the 6 to 18 age group. Larger representation from preschool children is mainly due to more defect detection at delivery points and later by frontline workers such as Accredited Social Health Activist (ASHA) and Anganwadi Worker (AWW) who can easily identify conditions such as cleft lip, club foot, and so on, also justifying for a higher proportion of congenital defects [5]. However the children suffering from disabilities and developmental delays are often missed resulting in them being picked by the health system at the school level screening program only for the disability to have progressed further resulting in loss to the child’s learning abilities; oftentimes leading to school dropouts. Therefore effective screening for disabilities and developmental delays at the initial stages (0 – 6 years) is crucial to making the program a success in terms of its effectiveness across different sections of society.

Another factor significantly affecting the program is the lack of compliance to RBSK referral advice on the part of the caregivers. Reasons for non uptake of services included concerns about wage loss and financial inability to continue treatment, long distance to the treatment centre, inconvenient timings, lack of time due to competing family issues, outright denial of the existence of impairment in the child, and stating that the problem would resolve as the child grows older [6]. However the most common reason for non compliance was being unaware of the referral. Oftentimes after being screened and referred the children are never followed up – it is assumed that once the children’s 4D’s have been brought to the notice of the caregivers and free treatment made available they themselves would act upon it. This has led to many children being lost to follow up.

RESEARCH QUESTION

How does the Rashtriya Bal Swasthya Karyakram (RBSK) program function in identifying disabilities and developmental delays among children aged 0-6 years (in Tripura), and what are the key factors associated with successful screening and early intervention outcomes?

OBJECTIVE

The objective of this research study is to make an assessment of the RBSK program's functionality in screening for disabilities and developmental delays among children aged 0 – 6 years in the North-eastern state of Tripura. The study specifically aims:-

1. To determine the coverage and reach of RBSK screenings amongst 0 – 6 year old children in Tripura.
2. To understand the community's perspective on RBSK screening including the various health variables influencing access.
3. To identify the barriers and enablers of RBSK program.

METHODOLOGY

The proposed study will be a cross-sectional mixed method study with two districts (1 good performing and 1 poor performing) representing the entire state of Tripura. The two districts (Dhalai – district 1 / Gomati – district 2) have been selected based on RBSK e-portal data for districts/blocks.

Good and poor performing districts have been selected based on the following criterion :

1. Newborns screened for birth defects by ASHA at home and healthcare worker at facility.
2. Children screened for 4Ds by MHTs.
3. Children treated by MHTs.
4. Children referred to DEIC by MHTs.
5. Children receiving intervention at DEIC.
6. Children who have undergone surgery at the higher centre for the health condition.

Data Collection Methods - Facility assessment using checklists, In-depth interviews (IDIs), Focus Group Discussions (FGDs)

Study Duration – 3 months

District selection criterion –

- Availability of a Functional DEIC.
- RBSK performance as per HMIS and e-Portal.

Block selection - Two blocks are to be selected for each district. Therefore 4 blocks have been selected (2 good performing and 2 poor performing) as representative of the state of Tripura. The blocks have been selected based on:

- Availability of operational Mobile health teams with at least 2 AYUSH Medical Officers, 1 ANM/ Staff Nurse, and 1 Pharmacist.
- RBSK Block MHT performance indicators (One good performing and one poor performing according to e-portal)

Facility Selection - The selection of representative facilities have been done on the basis of –

- 1 DEIC per District **(Total of 2 DEIC'S)**
- 2 MHTs per District **(Total of 4 MHT's)**
- 2 Block PHC/ HWC per District **(Total of 4 PHC/ HWCs/ Block CHC/ DPs)**
- 1 School per District **(Total of 2 Schools)**
- 2 AWCs per District **(Total of 4 AWCs)**
- Minimum of 10 ASHAs per Block for FGDs **(Total of 40 ASHA's)**

Stakeholders Involved – At the state level, the RBSK nodal officer is the one looking after the state wide operation of the RBSK program. Thus an in-depth interview with the nodal officer becomes important to get a state wide understanding of the RBSK program. Similarly the state ICDS officer and state PMJAY representative can provide a state level understanding of these allied programs. The DEIC manager at the district level is responsible for effective service delivery to the children suffering from the 4D's as well as acting as a referral linkage point for tertiary level care. The equipments available at the DEIC and the type of services provided by it are therefore important to understand the coverage and effectiveness of services provided. At the block level the MHT in-charge is responsible for the screening activities under the program which can very well be called as the backbone of the entire program. It is the MHT team that is tasked with identifying the children suffering from the 4D's (at the anganwadi and school level) and referring them to the DEIC's or other places up the referral chain depending on a case by case basis. An in depth interview with the MHT in-charge will thus provide this researcher with valuable insights about the community's perspective regarding the program as well as an understanding about the hesitancy amongst certain community's to avail treatment despite the free services made available. The ASHA's, Anganwadi workers and School teachers will add to this information by acting as

agents of the community – highlighting the challenges and obstacles that thwart the effectiveness of the program as well as provide locale remedies to solve such bottlenecks in service delivery. The beneficiaries/user’s awareness about the program, the challenges and barriers faced by them as well as their suggestions and remedies to strengthen the program is a must in any RBSK evaluation study.

Level	Stakeholders	Type of interview	Type of tool
District Level	DEIC Manager/In-charge	In-Depth Interview	Open ended questionnaire
Block Level	MHT In-charge	In-Depth Interview	Open ended questionnaire
	Anganwadi Worker		
	School teacher		
Community Level	Parents/caregivers of beneficiaries	In-Depth Interview	Semi-structured interview – open ended questions with probes
	ASHA	Focus Group Discussion	Open ended questionnaire
Facility Level	DEIC	DEIC Assessment Checklist	Structured tool with predefined answers
	MHT	MHT Assessment Checklist	
	Delivery points-DH/SDH/CHC/PHC	Facility Assessment checklist	

Data Analysis Plan - A semi-structured questionnaire will be used to conduct interviews with the above stakeholders. The FGD’s are designed to be open ended questions with the purpose of gathering in depth knowledge on particular themes like – the screening process (signs and symptoms) looked for in the children by the ASHA’s, the referral process as well as any counseling provided to caregivers/parents. The facility assessment checklists are structured questionnaires with pre-determined set of answers. Data is to be entered and analyzed using SPSS software.

Ethics Approval - A Participant Information Sheet (PIS) is provided to each stakeholder detailing the purpose and scope of the study as well as the procedures to be followed during the study. Moreover a consent form is filled by both the interviewer and the interviewee and one copy each is kept by the respective individuals. At the start of the interview the purpose and reason behind the study is again elaborated upon by the interviewer and verbal consent taken.

References

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