EVALUATING THE RASHTRIYA BAL SWASTHYA KARYAKRAM (RBSK) PROGRAM IN TRIPURA: IDENTIFYING DISABILITIES AND DEVELOPMENTAL DELAYS IN CHILDREN AGED 0-6 YEARS AND DETERMINANTS OF SUCCESSFUL SCREENING AND EARLY INTERVENTION

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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.

- 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."
- Early childhood development is a crucial element aiming towards children to be nourished, healthy, mentally alert, emotionally sound, socially competent, and ready to learn with better outcomes and higher education attainment.

Early Childhood Care And Development Through The Ages

Pre-natal to 1 month	1 Month to 3 years	3-6 years	5 – 8 years	8 – 11 years
Survival care and protection of newborn	Nutrition adequacy, immunization and cognitive stimulation	Socialization, psychosocial interaction, play and readiness for school through ECCE	Adjustment to formal school and learning of three R's while maintaining good health.	Completion of primary schooling and gain of improved life chances.

Background

- India's alignment to promoting, supporting, and protecting Early Childhood Development (ECD) on a global scale led to the launching of the Rashtriya Bal Swasthya Karyakram (RBSK) Program in 2013.

- Under the oversight of the MoHFW and National Health Mission (NHM), the program aims to provide free universal child health screening services, facilitating access to early intervention services throughout the nation.

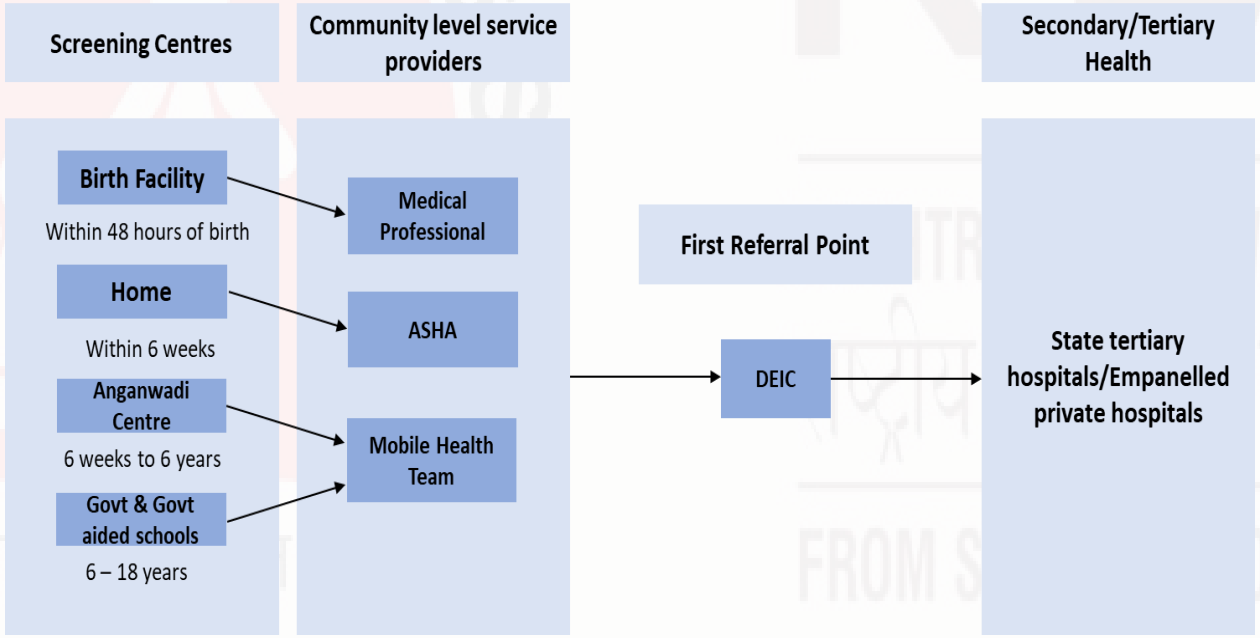
- The core activities of the RBSK program are centered around screening, early identification, and trans-disciplinary management of chronic health issues such as Birth Defects, Diseases, Deficiencies, and Developmental delays, collectively referred to as the 4 D's.

- Initially, the program targeted 30 specific conditions, but recently, seven new health conditions have been added (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).

Defects at birth	Deficiencies
Neural Tube Defect Down's Syndrome Cleft Lip & Palate / Cleft Palate alone Club foot (Talipes) Developmental Dysplasia of the hip Congenital Cataract Congenital Deafness Congenital Heart Diseases Retinopathy of Prematurity	Anaemia especially severe Anaemia Vitamin A deficiency (Bitot Spot) Vitamin D deficiency (Rickets) Severe Acute Malnutrition (SAM) Goiter
Childhood diseases	**Developmental Delays and Disabilities**
Skin conditions (Scabies, Fungal infection and Eczema) Otitis Media Rheumatic Heart Disease Reactive Airway Disease Dental Caries Convulsive Disorders	Vision Impairment Hearing Impairment Neuro-Motor Impairment Motor Delay Cognitive Delay Language Delay Behaviour Disorder (Autism) Learning Disorder Attention Deficit Hyperactivity Disorder
Congenital Hypothyroidism, Sickle Cell Anaemia, Beta Thalassemia	

Background

- RBSK aims to screen children from 0 to 18 years of age for the 4D's, with beneficiaries including children born at home or in public health facilities, pre-school children in rural areas or urban slums, and children enrolled in Government or Government-aided schools.
- Children born in health facilities are screened by health personnel within 48 hours of birth followed up within 6 weeks of birth under the Home-Based New-born Care package.
- Subsequent evaluations are conducted between the 3rd and 15th months (on the 3rd, 6th, 9th, 12th, and 15th months) under the Home-Based Care For Young Children Programme.
- Children identified with birth defects are integrated with the Janani Shishu Suraksha Karyakaram (JSSK) for further management.
- Pre-school children (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.



RBSK mechanism – adapted from Deloitte and UNICEF 2016 report

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?

Research Objectives

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

- **Study Duration:** 3 Months
- **Research Setting -** The study was conducted in the North-Eastern state of Tripura. Two districts, were selected from the state (1 good performing and 1 poor performing)
- **Study Design –** This study is a cross-sectional study based on primary research at various levels in Tripura
- **Sampling Design –**
- Selection of districts based on set criteria

Criteria for District Selection	
Availability of a functional DEIC.	
RBSK performance as per HMIS and RBSK e-portal.	Newborns screened for birth defects by ASHA at home and healthcare worker at facility.
	Children screened for 4Ds by MHTs.
	Children treated by MHTs.
	Children referred to DEIC by MHTs.
	Children receiving intervention at DEIC.
	Children who have undergone surgery at the higher centre for the health condition.

Methodology

- Selection of blocks based on set criteria:

	Districts	Block 1	Block 2
Tripura	Dhalai	Durgachowmuhani	Salema
	Gomati	Matabari	Amarpur

- Facility selection based on:

Criteria	Number Per District	Total
DEIC	1	2
MHT	2	4
Block PHC/HWC	2	2
SCHOOL	1	2
AWC	2	4
ASHA	10(Min) per block	40(Min)

Methodology

- Stakeholders and the type of interviews conducted in the two selected blocks

Type of interview	**District - Dhalai**	**District-Gomati**
In-Depth Interview	DEIC Manager/ In-charge	DEIC Manager/ In-charge
Focus Group Discussion	**Block -Durgachowmuhani**	**Block – Matabari**
In-Depth Interview	MHT – InCharge	MHT – InCharge
Focus Group Discussion	ASHA	ASHA
In-Depth Interview	Anganwadi worker	Anganwadi worker
In-Depth Interview	School teacher	School teacher
In-Depth Interview	Parents/caregivers of beneficiaries	Parents/caregivers of beneficiaries
	Block – Salema	**Block – Amarpur**
In-Depth Interview	MHT – InCharge	MHT – InCharge
Focus Group Discussion	ASHA	ASHA
In-Depth Interview	Anganwadi worker	Anganwadi worker
In-Depth Interview	School teacher	School teacher
In-Depth Interview	Patients/caregivers of beneficiaries	Patients/caregivers of beneficiaries

Methodology

- **Study tools with Stakeholders Involved –**

Level	Stakeholders	Type of interview	Type of tool	Key themes
District Level	DEIC Manager/In-charge	In-Depth Interview	Open ended questionnaire	Program overview, training of HR, MOUs with NGOs and Tertiary hospitals, Referral system, Socio-cultural factors affecting service-delivery, Roles and responsibilities of the CHWs
Block Level	MHT In-charge	In-Depth Interview	Open ended questionnaire	Functioning, HR and their training, Inter-departmental collaboration, monitoring and supervision
	Anganwadi Worker			Trainings, Collaboration with MHTs, Communicating with parents,
	School teacher			Coordination with MHTs, Communication channels, teenage marriages and school dropouts.

Level	Stakeholder	Type of interview	Type of tool	Key themes
Community Level	Parents/caregivers of beneficiaries	In-Depth Interview	Semi-structured interview – open ended questions with probes	Awareness about the program, Quality of counselling received, misconceptions associated with developmental delays, staff behaviour and satisfaction level of parents with services provided, challenges and barriers faced
	ASHA	Focus Group Discussion	Open ended questionnaire	Technical knowledge of the 4Ds, Training, Counselling of parents, Challenges faced
Facility Level	DEIC	DEIC Assessment Checklist	Structured tool with predefined answers	Infrastructure, equipments, core services provided, HR
	MHT	MHT Assessment Checklist		HR, Equipments, Registers maintained, Training of staff
	Delivery points- DH/SDH/CHC/PHC	Facility Assessment checklist		Functioning, equipments, reporting and documentation

Methodology

- **Data collection**

The data collection method included the following:

- Interview with state level officials at the state, district and block level.
- In-depth interview with the parents/caregivers of beneficiaries with 4D's at the community level
- Focus Group Discussions with frontline workers like ASHA's and AWW's.
- Facility assessment checklist at the service delivery points covering DH's, SDH's, CHC's, and PHC's.

- **Data Analysis**

- The qualitative data collected through the semi-structured interviews were converted into English transcripts from their original audio recordings.
- All coding and analysis have been done in Ms Excel.
- The key variables were selected from the transcripts after multiple readings.These key variables were coded and grouped into themes.
- The quantitative data collected through the facility assessment checklists were tabulated and presented in graphical format in the subsequent sections.

Findings

DHALAI (2023-24)														
Kamalpur RBSK MHT														
	Target	Screened	%screened to Target	Found +ve	% found +ve to screened	Birth defect	Deficiency	Disease	Developmental delay & diability	% of disability & developmental delay to found +ve	% of disability and developmental delay to total children screened	Refer to DEIC/DH/PHC/CHC/Tertiary Care	Treatment Done	% of treatment done to found +ve
0 - 6 Weeks	919	564	61.4	2	0.4	2	0	0	0	0	0	2	2	100
6 weeks - 6 years	9312	7736	83.1	666	8.6	5	33	607	7	1.1	0.09	666	641	96.2
6 Years - 18 Years	12519	11036	88.2	712	6.5	4	38	624	30	4.2	0.3	712	642	90.2
Salema MHT														
0 - 6 Weeks	596	78	13.1	0	0	0	0	0	0	0	0	0	0	0
6 weeks - 6 years	7123	5733	80.5	288	5.0	3	1	276	8	2.8	0.14	288	285	99.0
6 Years - 18 Years	5880	5669	96.4	150	2.6	3	1	125	21	7.3	0.37	150	147	98

Findings

GOMATI (2023-24)														
Amarpur RBSK MHT														
	Target	Screened	%screened to Target	Found +ve	% found +ve to screened	Birth defect	Deficiency	Disease	Developmental delay & diability	% of disability & developmental delay to found +ve	% of disability and developmental delay to total children screened	Refer to DEIC/DH/PHC/CHC/Tertiary Care	Treatment Done	% of treatment done to found +ve
0 - 6 Weeks	740	655	88.5	0	0	0	0	0	0	0	0	0	0	0
6 weeks - 6 years	5868	5717	97.4	521	9.1	3	0	505	13	2.5	0.23	521	521	100
6 Years - 18 Years	8551	8493	99.3	388	4.6	0	0	292	56	14.4	0.66	388	388	100
Matabari RBSK MHT														
0 - 6 Weeks	2693	234	8.7	2	0.9	2	0	0	0	0	0	2	2	100
6 weeks - 6 years	10,096	10,096	100	180	1.8	12	4	109	55	30.6	0.54	180	168	93.3
6 Years - 18 Years	21,161	13,696	64.7	739	5.4	5	1	406	127	17.2	0.93	739	674	91.2

Findings

- The above table evidently shows that with increase in age the number of disability & developmental delay cases increases out of the total number of children screened in both the districts of Dhalai and Gomati.
- The percentage of disability and developmental delay to found positive also increases also increases with age. In case of Salema MHT the percentage increases from 0 to 7.3.
- The percentage of disability and developmental delay cases also increases with increase in the total number of children screened. Hence more the number of children screened, more are the chances of disability and developmental delay children being identified.
- Majority of the disability and developmental delay cases continue to be detected at the 6-18 Years age group. The ideal time to identify developmental delay cases happens to be four months from delivery and up to the age of one year (maximum). After six years it becomes too late. The disability by that time develops into deformity. Moreover, the disabled children seldom go to school and as the screening point for 6 to 18 years old children happen to be the school, it can be assumed that those detected at the school level only represent a minor subset of the children suffering from disability or developmental delays. The delivery point and the ASHA's thus becomes extremely important for the early detection of developmental delays in children.

"At Gomati District Hospital ... the scale at which delivery happens ... they simply do not have enough time to do a thorough screening of each and every child...even the PHC...they do not." - DEIC Gomati Physiotherapist

District Early Intervention centres

- There is shortage of manpower at both the visited facilities. While there is no Staff nurse at DEIC Dhalai, at Gomati a full-time audiologist, an early interventionist and a pediatrician are immediately needed. Due to shortage of staff at the facility (especially speech therapist and early interventionist at Gomati DEIC) patients often have to visit private practitioners who are usually located at Agartala increasing the Out-of-pocket expenditure significantly.
- While the ASHA' s play a crucial role in identifying and referring children suffering from disability and developmental delays to the DEIC's in the initial days of a child's life as part of the HBNC and HBYC programs, there was a lack of co-ordination between the DEICs and the ASHAs and Anganwadi Workers. Both the InCharges acknowledged the crucial role that the ASHAs and Anganwadi workers play in the program but highlighted the lack of training amongst them. While visible birth defects are more easily identifiable, disability and developmental delays are not and thus require periodic and continuous training (and not a one-day orientation program) so that ASHAs can contribute in the community screening process more effectively.
- The Gomati DEIC caters to four districts – West Tripura, South Tripura, Sipahijala and Gomati- thus serving a wide geographical area. The patients who come from far-flung areas (hilly and tribal areas) often stop coming after the first or second visit. Despite repeated phone calls and sensitization (by the DEIC manager and the local ASHAs), these patients do not follow up. Such parents, though understanding the importance of continuing treatment for their child, cannot afford the transportation costs.

"Challenge is this...if follow up can be increased...transport...if we can provide financial support to certain families who come from far away...then we hope there will be more follow-ups...there will be more awareness amongst people." - Physiotherapist, DEIC Gomati

Mobile Health Teams

- The MHTs are assigned a daily screening target of 120 children. All the four MHT teams considered this target unachievable, especially considering the geography and terrain of a state like Tripura. The average number of children screened each day hovered around 70-80. Moreover, fulfilling this target oftentimes meant compromising with the quality of the screening itself as well as effective communication with the parents/caregivers of the children identified with the 4D's.
- Shortage of manpower - There are a total of 58 blocks in Tripura and 48 MHT teams. Of these only 46 are functional. Gomati, moreover, has a total of 8 blocks and only 5 MHT teams to cover them. Due to this acute shortage the MHT team of Matabari block is covering two blocks- Matabari and Kakraban. The anganwadi centres and schools at both these blocks are only covered once a year by the MHT team. The MHT team at Amarpur (Gomati district) has no ANM and as such the workload is distributed among the remaining three members (MMO, FMO and a pharmacist). Shortage of manpower is thus a huge barrier to service delivery in Tripura.
- There is a lack of awareness at the community regarding the RBSK program. The ASHAs and the Anganwadi workers need more training on the RBSK program. Even after referral and arrangement of transportation services some patients are unwilling to take the treatment. The ASHAs and Anganwadi workers have a key role to play in convincing the parents by acting as effective agents of the RBSK program

"People are not that much aware of our activities. We need to aware people…like…after every 3 months or 4 months we can arrange a meeting with the Anganwadi workers, ASHAs and with the School teachers also… for the smooth communication" **– MHT InCharge Salema**

Community Health Workers

- Most of the ASHAs were provided with a brief orientation about the 4D's as part of the HBNC and HBYC program. RBSK specific training was provided only once (one day training) before the interview date.
- Lack of training - Most of the diseases identified by the ASHAs are visible birth defects as they are easier to catch to the naked eye. Most of the ASHAs had not found any cases of disability or developmental delays in their community despite working for decades. Lack of training amongst the ASHAs is thus a serious challenge.

"Training if it happens will be good. We will get to know more and learn new things. One day training is not enough... the training was so long ago...we have forgotten many things." - ASHA Kamalpur

- ***Lack of awareness in the community*** - Convincing the parents of children (suffering from developmental delays) living in tribal areas oftentimes becomes a challenge for the ASHAs. In many regions even after repeated counseling by the ASHAs the parents do not continue the treatment. In the case of developmental delays, the parents are oftentimes not willing to accept the seriousness of their child's condition.
- Lack of incentive - As the ASHAs do not have any incentive associated with the RBSK program (Screening, referral and management), they are mostly hesitant to do thorough screening and counselling of the parents. They mostly consider it an added responsibility over and above their daily work.

"If under any ASHA, a 4D child is identified...if that ASHA could be incentivized...then the ASHA can make more visits to the child." - ASHA facilitator Kamalpur

Anganwadi Worker

- The Mobile Health Teams usually inform the Anganwadi workers a day prior to their planned visit (at one of the Anganwadi centres –Shundar Ram ShisuBihar- the MHT team often visits uninformed).
- Despite the AWWs efforts to convince the parents, on some occasions some children remain absent on the day of the screening.

"The mother's need to be made more aware...Guardians are the main." - AWW Garjee village, Matabari block.

- *No training* - Since no RBSK related training has been provided to the Anganwadi workers, they do not have any grasp over the program and the 4D's. They are only aware that a RBSK team comes to screen their children at the centre and that it is their duty to ensure that the maximum number of children are present on the day of the screening. Since the AWWs themselves are unaware of the technicalities of the program, they are unable to communicate and convince the parents and caregivers to take their children to the referred health facilities.

"We have not been provided with any training and that is why i am not able to clearly understand." - AWW Garjee village, Matabari

- There were no posters or banners related to the RBSK program at any of the Anganwadi centres.
- Whenever the Anganwadi workers find any suspected cases of 4D's, amongst the enrolled children under them they contact the local ASHAs and through the ASHAs contact the MHT teams. The counseling of parents (of children suffering from developmental delay or disability) is usually done by the MHT teams.

School Teachers

- On the day the MHT visits the schools (once a year) the assigned schoolteacher orchestrates the entire screening process- from getting the students seated at assigned classrooms to maintain the decorum while the students are screened- they play an important role in the entire process.
- Once the screening is completed and the positive children identified, the schoolteachers act as communication channels informing the parents of their child's conditions and the future actions recommended by the MHT team.
- In Tripura, there is an issue of teenage marriage amongst girls of 16-18 years of age. These children cannot be followed up and are the missing children from the system.

"This is a girl's school...usually girls get married at 18-19 years. Tracking such girls becomes impossible. They remain absent for long." - School principal, Bhagini Nivedita Girls HS School Gomati

- The regular students are involved in the MHT screening process. The school WhatsApp groups are used to inform the students about the visit of the MHT teams. On the day the MHT teams visit a student list (class-wise) of the students present is prepared.
- Lack of awareness in the community - even after repeated intimation they are hesitant and do not understand that their child needs treatment as soon as possible. There is the tendency to delay the treatment. Better counselling of parents by domain experts could significantly reduce the gap between disease identification and treatment.
- More frequent visits by the MHT teams with prior intimation is required. The transportation costs are also a big challenge in terms of convincing parents to take their children to the health facilities.

Parents/Caregivers of beneficiaries

- Lack of awareness about the program in the initial years- Due to lack of awareness about the program in general and misconceptions associated with developmental delays many parents were initially hesitant about taking treatment. They failed to realize the seriousness of their child's condition. Many times the belief was that all will get better with time.

"His elder brother also had speech delay...had learnt to speak late. We had thought he was also the same...he would also speak later. The elders in our community also said this is normal...that boys learn to speak late...told me to have patience and not go to the doctor." - Parent of Autistic and speech delay child

- There is a lot of shame associated with disability in many of the remoter villages of Tripura. In such cases, due to lack of awareness about the program and extreme poverty and belief in superstitions the parents are often hesitant to act and are prone to take local remedies (Ojhas and superstitious healers).

"Saying all this in our village is not easy...villagers say take him to ojhas [spiritual healers] ...maybe he has been possessed...they say all this. I don't believe and that's why i did not want to spread." - Parent of RBSK beneficiary

- Lack of HR at the DEICs- The lack of HR at the DEICs is also a pressing concern. At DEIC Gomati there was no speech therapist posted because of which parents of children suffering from speech delay had to take their children to Agartala which further increased the transportation cost and the out-of-pocket expenditure of parents.
- most of the parents feel that more RBSK related information needs to be disseminated in society and more campaigns need to be organized. This will have two advantages – More awareness will result in more informed parents which will increase self-referral as well as prompt action post follow up and continued treatment. The other benefit would be de-stigmatization of disability and developmental delay children.
- **DEIC Beneficiary Suggestions**
- Reimbursement of transportation costs or RBSK van services provided to bring the children living in remoter areas to the DEICs on the assigned dates.
- Special Educators at Schools to teach the special children.
- More camps and awareness generation activities to build a society more sensitive to the needs of such children.
- Arranging games or activities designed to improve the cognitive abilities of delayed children at the DEICs so that they can learn while playing.

Discussion

- Many beneficiaries at the DEICs were satisfied with the services, but transportation costs and lack of HR were significant barriers.
- The parents who were able to afford the transportation cost associated with repeated and continued visits to the DEICs had received proper counseling and testified to the improvement in their child's condition after receiving treatment. Families unable to afford transportation and associated costs faced challenges in accessing DEIC services.
- Most patients undergoing therapy at the DEICs were between 3 to 6 years old.
- Lack of training among ASHAs hindered quick referral and early intervention.
- ASHAs were comfortable screening visible birth defects but struggled with identifying developmental delays.
- Mothers often delayed seeking help due to lack of awareness and late recognition of their child's condition.
- MHT teams were overburdened by screening targets and struggled with community awareness and convincing parents.
- Poverty prevented some parents from utilizing free DEIC services due to transportation costs.
- Thus, lack of awareness about the program at the community level is affecting both ends of the service delivery spectrum – the beneficiaries as well as the service delivery staff
- The parents without proper information remain hesitant to take their children to the DEICs while due to lack of information and the parents failing to understand the seriousness of their child's condition and the benefits of continued treatment the service delivery staff are unable to convince the parents to continue their child's treatment

Conclusion and Recommendations

- To elevate the delivery of our program, it is imperative that training across various activities and audiences be meticulously integrated into our framework. The essence of these training needs is articulated as follows:
- **Continuous refreshing for MHTs**: Regular refresher training is necessary to maintain the proficiency and effectiveness of Mobile Health Teams (MHTs) beyond the initial five-day orientation.
- **Cultivating Communication Skills and Counselling skills:** MHTs need training in interpersonal communication and counselling to effectively educate and support caregivers.
- **Enlightening through IEC/BCC:** Health personnel at delivery points should be trained to generate better awareness about the program, utilizing media channels, local fairs, and culturally relevant events.
- **Improved state coordination**: State-level program officials require training to engage with RBSK stakeholders and establish clear communication channels, ensuring a unified and effective program.
- **Realistic screening targets**: Daily screening targets for MHTs should be revised to ensure quality and accuracy, considering the unique conditions of each state, such as challenging terrains in Tripura.
- **Enhancing Transportation services for beneficiaries**: Implement monthly transportation services for groups of RBSK beneficiaries and caregivers, collaborating with local transport services and establishing pick-up points in central locations.
- **Including additional health conditions:** Expand the list of conditions under RBSK to include common health issues specific to Tripura, such as imperforate anus.
- **Departmental convergence and partnerships:** Strengthen collaboration between the Health Department and other departments like Women and Child Development, Human Resource Development, and Social Justice and Empowerment through regular meetings and formal training.
- **Role of NGOs:** Utilize the local knowledge, community trust, and expertise of NGOs to enhance program effectiveness and support the children of Tripura.

Conclusion and Recommendations

Policy Recommendations -

- Focus on skills training of the Community Health workers (ASHAs and AWWs).
- Reevaluate and re-visit the daily screening target for the MHTs especially for a geographically sensitive place like Tripura.
- Regular and periodic refresher trainings for the MHT MOs and pharmacists.
- Enable transportation services for the DEIC beneficiaries (or subsidize a percentage of the transportation costs based on the economic status of the family and the number of visits per week).
- Addition of other common diseases that are endemic and specific to certain states in the 0-18 age group to provide wholistic care under the RBSK program.
- Foster better coordination and cooperation between other departments (WCD, ICDS) to further strengthen the program at the grassroots level.
- Increase the number of MHTs such that there are atleast an MHT per block.