

Assessing Caregiver adherence to referral advice in the RBSK program: Evaluating the Effectiveness of Community-based Screening and District-based Intervention Services for Children with Disabilities in Rajasthan



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What Is **Rashtriya Bal Swasthya Karyakram** (RBSK)?



INTRODUCTION

The Ministry of Health & Family Welfare, Government of India, under the National Health Mission launched the Rashtriya Bal Swasthya Karyakram (RBSK), an innovative and ambitious initiative, which envisages Child Health Screening and Early Intervention Services, a systemic approach of early identification and link to care, support and treatment.

RBSK aims to provide comprehensive healthcare services to children nationwide, with a focus on early diagnosis and intervention for various health concerns. In Rajasthan, where geographic and socioeconomic factors affect healthcare access, RBSK plays a crucial role in meeting the health needs of young children and adolescents. RBSK mandates regular health exams, including evaluations of growth, development, vision, hearing, and mental health. Specially formed health teams, comprising community health workers, medical experts, and accredited social health activists (ASHAs), screen children in both remote rural areas and metropolitan centers. These teams travel across the state to ensure early detection and prompt treatment of health problems, preventing long-term difficulties that could hinder children's development and future prospects. Since its establishment, RBSK has significantly improved the equity and accessibility of healthcare for children in Rajasthan.

The program aligns with national and international health objectives, such as the Sustainable Development Goals (SDGs), particularly Goal 3, which focuses on ensuring healthy lives and promoting well-being for all ages. By emphasizing preventative healthcare and adopting an integrated approach, RBSK not only addresses current health issues but also strengthens the fundamental public health infrastructure at the local level. This review aims to analyze the implementation and effects of RBSK in Rajasthan, shedding light on the program's successes, challenges, and areas for improvement. The objective is to provide evidence-based recommendations to inform policy decisions and enhance the program's effectiveness in meeting the healthcare needs of Rajasthan's children by evaluating its reach into marginalized populations, improving health outcomes, and fostering community engagement. The National Rural Health Mission (NRHM), founded on April 12, 2005, aimed to provide affordable, high-quality healthcare to rural communities, especially vulnerable populations. On May 1, 2013, the National Urban Health Mission (NUHM) was included as a sub-mission. RBSK, launched in 2013, examines children for 40 common health issues under the four Ds: defects at birth, illnesses, deficiencies, and development delays. The program serves children from infancy to age 18, ensuring early identification and free treatment, including surgeries at authorized facilities.

LITERATURE REVIEW

Implementation of RBSK in Rajasthan

- Bhutta et al. (2013) emphasized early childhood treatments' importance in improving health outcomes, advocating for comprehensive programs like RBSK to address developmental delays and impairments.
- Kumar and Goel (2014) highlighted the role of community health workers in enhancing healthcare access in remote areas, focusing on their contribution to efficient RBSK implementation.
- Gupta and Shah (2015) evaluated RBSK's efficacy in detecting congenital anomalies and other health issues early, emphasizing its preventive healthcare benefits.
- Srivastava et al. (2016) assessed the challenges and possibilities of expanding RBSK services nationwide, noting variations in implementation strategies and outcomes across different states.
- Agarwal and Shah (2017) examined the integration of mental health services within RBSK, advocating holistic healthcare approaches to address psychosocial issues affecting children.
- Singh et al. (2018) investigated RBSK's impact on reducing newborn mortality rates and improving child health indicators, highlighting significant improvements in states effectively implementing the program.
- Sharma and Sharma (2019) evaluated RBSK's effectiveness, focusing on data management, monitoring, and therapy evaluation for pediatric patients.

RBSK Implementation in Rajasthan

- Framework: Operates with mobile health teams, specialized RBSK supervisors, and district early intervention centers (DEICs), aiming for routine health screenings, referral services, and follow-up treatments in schools and Anganwadi facilities.
- Statistics: Rajasthan has achieved significant screening coverage (70% in 2018–2019), identifying health issues like malnutrition and developmental delays.
- Early Intervention: DEICs provide critical services including speech therapy, physiotherapy, and dietary support; over 60% of referred clients receive timely treatment.

Challenges in Implementation

- Infrastructure and Resources: Lack of medically trained staff in remote areas and inadequate medical infrastructure.
- Follow-up and Continuity of Care: Challenges in ensuring adherence to treatment plans, especially in rural settings.
- Community Awareness: Greater community involvement needed to enhance program reach and effectiveness.

Comparative Evaluation

- Outcomes: Better early intervention outcomes observed in states with higher community participation and developed healthcare infrastructure like Tamil Nadu and Kerala.

Results and Effects

- Health Improvements: Decreased prevalence of untreated congenital illnesses and nutritional deficiencies; improved academic outcomes and reduced dropout rates among children with developmental delays.

Policy Recommendations

- Expansion of DEICs: Increase facilities and capabilities to manage workload effectively.
- Capacity Building: Continuous training for healthcare providers and community workers to enhance screening accuracy and care quality.
- Integrated Services: Coordinate RBSK with existing child health programs for comprehensive care delivery.
- Monitoring and Assessment: Establish robust protocols to track program progress and outcomes accurately.

In conclusion, while Rajasthan's RBSK has made substantial strides in child health, addressing infrastructure gaps, enhancing community participation, and implementing robust monitoring are crucial to sustain and improve its impact statewide.

OBJECTIVE

This study aims to assess how caregivers follow and adhere to referral advice given through the RBSK program.

The overarching goal is to evaluate the effectiveness of the current community-based screening and district-based intervention service model for children with disabilities, focusing on factors influencing caregiver decision-making and service utilization.



METHODOLOGY

Study Design: Descriptive cross-sectional design.

Study Established: Rural and urban areas of rajasthan

Population Size: The study included 115 caregivers of children with disabilities who were referred by the RBSK program.

Data Collection Method:

Caregivers were contacted by the RBSK mobile team.

A semi-structured questionnaire was used to collect data on:

- (a) whether the caregiver was aware of the child's health issue, and whether any treatment had been sought prior to the RBSK screening
- (b) actions taken after receiving the referral advice from the RBSK team
- (c) current medical care and therapies being provided to the child and
- (d) reason for non-compliance or discontinuation of treatment. Data was entered and analysed in Microsoft Excel, and described using simple proportions.

RESULTS

Major Conditions identified and referred from Community Settings by RBSK Mobile Teams

Number of Major Conditions identified: 31

Number referred from Community Settings: 647

The provided data categorizes various conditions affecting children into major birth defects, minor anomalies, genetic disorders, and developmental disabilities.

Major birth defects include congenital heart defects, cleft lip/palate, limb and skeletal deformities, and others impacting vital organs or physical structures.

Minor anomalies encompass conditions like strabismus (eye misalignment), tongue tie, and deviant nasal septum.

Genetic disorders such as thalassemia and muscular dystrophy involve inherited abnormalities affecting blood or muscle function.

Developmental disabilities cover issues like speech delay, intellectual impairment, and conditions affecting motor skills or sensory perception. Each category represents diverse health challenges requiring specialized care and support for affected individuals.

Table 1: Major Conditions identified and referred from Community Settings over the seven- month period by RBSK Mobile Teams

Condition	Number of referrals	Condition	Number of referrals
Major birth defects		Minor anomalies	
Congenital heart defects	96	Strabismus	122
Down syndrome	14	Tongue tie	56
Cleft lip/palate	12	Phymosis	40
Limb and skeletal deformities	10	Deviant nasal septum	20
Congenital talipes equinovarus	7	Ptosis	9
Eye / Ear malformations	4	Polydactyly	2
Neural tube defect	2	Undescended testicles	2
Microcephaly	2	Congenital umbilical hernia	2
Multiple disabilities	1	Hypospadia	1
Genetic disorders		Developmental disabilities	
Thalassemia	11	Speech delay/difficulty	116
Sickle cell anemia	3	Intellectual impairment	60
Muscular dystrophy	3	Hearing impaired	19
Achondroplasia	1	Delayed milestones	15
Diamond-Blackfan anemia	1	ADHD, Autism	6
		Cerebral palsy	5
		Visual impairment/ Blindness	4
		Hearing and speech impaired	2

Caregiver Awareness and Treatment

- 64 caregivers were aware of their child's health issues before screening due to symptoms.
- 39 of these caregivers had started or stopped treatment.
- 25 caregivers did not seek treatment despite a diagnosis.
- Among children referred for treatment, 60% with major conditions received it.
- Only 4% of those with minor anomalies received treatment.
- Most children with developmental disabilities (24 out of 29) were not receiving therapy.

Table 2: Characteristics of Caregivers and Children	
	N
Residence	
Urban	69 (60%)
Rural	46 (40%)
Distance to DEIC (in kms)	
<10	21 (18%)
11- 35	57 (49%)
36-65	8 (7%)
>66	29 (25%)
Caregiver presence at screening	
Yes	57 (49%)
No	49 (43%)
Data missing	9 (8%)
Age group (years)	
0-4	37 (32%)
5-9	45 (39%)
10-14	29 (25%)
15-19	4 (3%)

Caregiver Awareness, Compliance, and Treatment Challenges

Caregiver Awareness Prior to RBSK Screening

- 64 out of 115 caregivers (56%) were aware of health issues before screening.
- Initiated/discontinued treatment: 39
- Did not seek healthcare despite diagnosis: 25

Compliance and Treatment Status

- Children referred for CHD: 38
- Treated/awaiting surgery: 60%
- Other major disorders treated: 60%
- Untreated children with diagnosed conditions: 6
- Minor anomalies accessing treatment: 4%
- Developmental disabilities not receiving therapy: 24 out of 29

Table 3: Reasons for Non - compliance/ Treatment Dropout						
	Condition	Sample (N)	Treatment status	N	Reasons for non-compliance/ treatment dropout	N
A. Major birth defects						
1	Congenital heart defects	38	Treatment completed/ongoing under RBSK	21	Did not know where to go, long distance to treatment centre, competing family issues, loss of wages	3
			Undergoing treatment at private hospital	8	Caregiver refusal (child with Down syndrome)	1
			Not CHD	2	Did not give substantial reasons	3
2	Cleft lip/palate	5	Surgery completed	3	Competing family issues	1
			Awaiting surgery	1		
3	Limb and skeletal deformities	4	No treatment	2	Did not know about referral	1
					Stopped due to financial reasons	1
4	Congenital talipes equinovarus	2	Treatment completed	1	Not contacted by team with further information	1
5	Neural tube defect	1	Incontinent, treatment ongoing at a private hospital	1	-	
B Genetic disorders						
6	Thalassemia	5	Treatment at public facilities	4		
			Treatment at private facility	1		
7	Sickle cell anemia	2	Treatment at public facility	1		
			Treatment at private facility	1		
C Minor anomalies						
8	Strabismus	12	Undergoing treatment at empanelled hospital	2	Long distance Did not give substantial reasons	2
			Undergoing treatment at private hospital	2		
9	Tongue tie	3	Undergoing treatment at public facility	1	Time inconvenience	2
10	Phymosis	5	Undergoing treatment at private hospital	1	Long waiting hours, poor communication by doctors	1
					Financial problems	1
					Denial (considers problem to be inconsequential)	2

Reasons for Lack of Compliance/Treatment Dropout

Non-Compliance:

- Financial constraints: 21.5%
- Distance to treatment centers: 13.5%
- Inconvenient timings: 6.5%
- Family issues: 15%
- Denial of condition: 3.5%
- Belief problem will resolve on its own: 1%

Discontinuation:

- Long travel distances: 9%
- Transport difficulties: 1.5%
- Long waiting times: 4.5%
- Irregular specialist visits: 1%
- Poor communication: 7%
- Financial issues (indirect costs): 18.5%
- Unaware of referrals: 3%
- Uninformed about screenings: 1%

	Condition	Sample (N)	Treatment status	N	Reasons for non-compliance/ treatment dropout	N
11	Deviant nasal septum	3	Undergoing treatment at private hospital	1	Specialist did not come Did not know where to go	1 1
12	Ptosis	4	Undergoing treatment at a private hospital Awaiting surgery	1 1	Long waiting hours, dissatisfied with the service Not able to recall the reason	1 1
13	Undescended testicles	1			Treatment initiated and stopped due to competing family issues	1
14	Hypospadias	1	-		No reason cited	1
D Developmental disabilities						
15	Speech delay/ difficulty	8	Treatment completed	1	Child started to speak normally Will grow up and speak properly Time inconvenience Possible incorrect diagnosis as child "can speak but forgets things" No referral given	1 2 1 1 2
16	Intellectual impairment	7	Taking Ayurvedic treatment	1	No improvement Competing family priorities Long distance and waiting times Did not know about referral	2 1 2 1
	Condition	Sample (N)	Treatment status	N	Reasons for non-compliance/ treatment dropout	N
17	Hearing impaired	6	Started using hearing aid	1	Long distance and time consuming Doctor did not call back Dissatisfied with the service Did not know about the referral	2 1 1 1
18	Delayed milestones	3	Undergoing treatment at public facility Undergoing treatment at private facility	1 1	Long distance, wage loss, doctors did not give proper advice, time inconvenience	1
19	Cerebral palsy	2	Taking therapies	1	Time inconvenience	1
20	Visual impairment/ Blindness	3	Will be operated after a few years	1	Doctor did not call back Can see now	1 1

Key Results and Findings:

64 caregivers were aware of their child's disability, most children remained untreated.

After screening and referral by the RBSK team, compliance was high for treatable conditions like congenital heart defects.

Treatment was discontinued for 83% (24 out of 29) of children with developmental disabilities.

Reasons for discontinuation included lengthy waiting times, distance to facilities, difficulty in transporting the child, loss of wages, and denial of the child's disability.

The results indicated that the RBSK program offers treatment opportunities for children who remain undiagnosed and untreated in the community. However, providing rehabilitation services solely at district centers poses a barrier to service uptake. Alternative models, such as early childhood development screening and integrating rehabilitation services at the primary healthcare level, may be more feasible for delivering services to children with disabilities in Rajasthan.

DISCUSSION

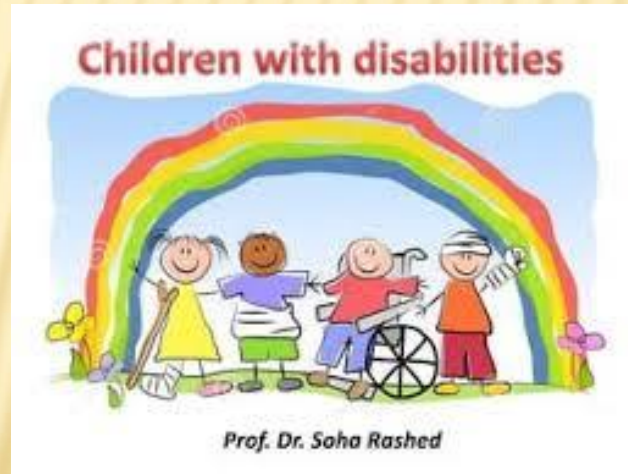
The RBSK model's community-based screening and district-level intervention services are pivotal in diagnosing and managing disabilities in resource-constrained settings like Rajasthan. The program's community-based screening effectively identified untreated or poorly treated children with birth defects and developmental disabilities, enabling timely medical interventions. However, centralizing rehabilitation services at the district level posed challenges, as many caregivers discontinued therapies due to repeated visits, long waiting times, transportation issues, and financial constraints.

Caregiver reports highlighted the need for better communication from RBSK doctors, as confusion over referral advice was common. The study noted a gap in genetic counseling referrals for severe genetic disorders, emphasizing the need for this service. The findings also pointed to the importance of early intervention, suggesting that RBSK should engage community healthcare providers more effectively.

Caregivers indicated the necessity of receiving information on managing daily activities and home-based treatments to reduce transportation costs. Enhancing disability pensions and financial support was also crucial to prevent financial strain on families. Despite a small sample size, the study provided valuable insights into improving the RBSK model's effectiveness and accessibility, advocating for integrating rehabilitation services into primary healthcare for better community access.

CONCLUSION

Community-based screening facilitates access to medical and rehabilitation care for children with birth defects and developmental disabilities who remain undiagnosed and untreated in the community. Centralised district level medical care and public-private partnership for specialist care provide an opportunity for expanding the scope of public health services. The policy recommendations of this study are that rehabilitation services for developmental disabilities need to be decentralised and incorporated at the level of primary healthcare, close to communities, in order to ensure their uptake. Routine monitoring of early child growth and development might be an alternative approach for early identification of birth defects and developmental disabilities.



RECOMMENDATION

Decentralize Services:

Make rehabilitation services available at primary health centers to reduce travel burdens for caregivers and ensure timely therapy sessions for children.

Enhance Community Engagement:

Train and equip local health workers to identify and manage health issues early.

Comprehensive Caregiver Support:

Provide detailed information, counseling, and support services to help caregivers manage their child's healthcare needs.

Improve Communication and Follow-up:

Ensure caregivers receive clear information about referral advice and follow-up steps, with regular follow-up by healthcare providers.

Monitor and Evaluate:

Continuously monitor and evaluate the RBSK program to identify gaps and improve strategies.

Promote Early Childhood Development Screening:

Integrate routine early childhood development screening into primary healthcare services for early identification and intervention.

RESEARCH QUESTIONNAIRE

How often are health check-ups conducted under RBSK in Rajasthan?

- a) Monthly
- b) Quarterly
- c) Bi-annually
- d) Annually

Which age group is primarily targeted by the RBSK program?

- a) 0-6 years
- b) 6-10 years
- c) 10-15 years
- d) 15-18 years

What is the primary focus of RBSK?

- a) Immunization
- b) Preventive healthcare
- c) Curative healthcare
- d) All of the above

How are severe health conditions addressed under RBSK?

- a) Referral to specialists
- b) Local treatment
- c) Ignored
- d) Home remedies

Which type of professionals are part of the RBSK team?

- a) Doctors and Nurses
- b) ASHA Workers
- c) Pharmacists
- d) All of the above

How is the health status of children tracked in RBSK?

- a) Paper records
- b) Digital health cards
- c) Verbal reporting
- d) Annual surveys

What is a common health issue identified among children in RBSK screenings?

- a) Malnutrition
- b) Dental problems
- c) Vision impairment
- d) All of the above

What is the frequency of follow-up for children identified with health issues under RBSK?

- a) As needed
- b) Weekly
- c) Monthly
- d) Annually

What is the role of ASHA workers in RBSK?

- a) Conduct health screenings
- b) Educate parents
- c) Facilitate referrals
- d) All of the above

Which of the following is a key objective of RBSK?

- a) Reducing child mortality
- b) Enhancing child education
- c) Promoting sports among children
- d) Ensuring clean drinking water

Which health indicator is not typically measured during RBSK check-ups?

- a) Weight
- b) Height
- c) IQ level
- d) Vision acuity

How does RBSK contribute to the overall health system in Rajasthan?

- a) By providing additional workforce
- b) By reducing the burden on hospitals
- c) By early identification and treatment of diseases
- d) By promoting traditional medicine

Which of the following services is not provided under RBSK?

- a) Free medication
- b) Free surgeries
- c) Free transportation for medical visits
- d) Free education

How is the success of RBSK measured annually?

- a) Number of children screened
- b) Number of health camps organized
- c) Improvement in health indicators
- d) All of the above

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THANK YOU