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**RBSK**

RASHTRIYA BAL SWASTHYA KARYAKRAM  
राष्ट्रीय बाल स्वास्थ्य कार्यक्रम  
FROM SURVIVAL TO HEALTHY SURVIVAL

## Formative Research Report on RBSK

*'From Survival to Healthy Survival'*

July 2016



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Re: Submission of the Final Formative Research Report

Dear Ms. Sharma and Dr. Khobragade,

We are pleased to submit the attached final Formative Research Report covering the Knowledge, Attitudes, Beliefs and Practices (KABP) for *Rashtriya Bal Swasthya Karyakram (RBSK)*, an ongoing Child Health Programme under National Health Mission.

In the context of limited data on this topic in the public domain, this study brings out the KABP findings of caregivers of children with defects, developmental delays including disabilities, thus highlighting its uniqueness and its value. The findings from this study inform the design of a social and behavioural change communication framework for an on-going Child Health and Screening Programme (RBSK) under National Health Mission. The implementation of the National Communication Framework for RBSK is expected to improve the utilisation of RBSK services. The National Communication Framework for RBSK is presented as a separate report. We want to thank you for your strong support and participation through the course of the study.

Please do not hesitate to contact me ([anupajoshi@deloitte.com](mailto:anupajoshi@deloitte.com)) if there are any queries or if you should require any additional information regarding our report.

Yours sincerely,

Anupama Joshi

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### List of Abbreviations Used

2Ds	Birth Defects and Developmental Delays
4Ds	Birth Defects, Developmental Delays, Deficiencies and Diseases
ALIMCO	Artificial Limbs Manufacturing Corporation of India
ANC	Ante-Natal Care
ANM	Auxiliary Nurse Midwifery
APL	Above Poverty Line
ARI	Acute Respiratory Infections
ASHA	Accredited Social Health Activist
AWC	Anganwadi Centre
AWW	Anganwadi Worker
AYUSH	Ayurveda, Yoga and Naturopathy, Unani, Siddha and Homoeopathy
BCC	Behaviour Change Communication
BDS	Bachelor of Dental Science
BEO	Block Education Officer
BPL	Below Poverty Line
CDPO	Child Development Programme Officer
CGHS	Central Government Health Services
CHC	Community Health Centre
CHD	Congenital Heart Diseases
CS	Chief Surgeon
CWSN	Child With Special Needs
DA	Dearness Allowance
DDRC	District Disability Rehabilitation Centres
DEIC	District Early Intervention Centres
DH	District Hospital
DHO	District Health Officer
DPO	District Programme Officer
DWCD	Department of Women and Child Development
FGD	Focused Group Discussion
FLW	Front Line Worker
FMR	Financial Management Report
GP	Gram Panchayat
HBNC	Home Based New Born Care
HPD	High Priority District
HR	Human Resource
ICDS	Integrated Child Development Services
IDI	In-Depth Interviews
IE	Inclusive Education
IEC	Information, Education and Communication
IFA	Iron and Folic Acid
INR	Indian National Rupees

IP	Informal healthcare Provider
KABP	Knowledge, Attitudes, Beliefs, and Practices
LMO	Lady Medical Officer
MBBS	Bachelor of Medicine and Bachelor of Surgery
MG	Mothers Group
MHRD	Ministry of Human Resource Development
MHT	Mobile Health Team
MIS	Management Information System
MO	Medical Officer
MoHFW	Ministry of Health and Family Welfare
MoU	Memorandum of Understanding
MRW	Multi-purpose Rehabilitation Worker
MoSJE	Ministry of Social Justice and Empowerment
NA	Not Applicable
NGO	Non-Governmental Organization
NHM	National Health Mission
NRC	Nutritional Rehabilitation Centres
OBC	Other Backward Caste
PG	Post Graduate
PHC	Primary Health Centre
PIP	Programme Implementation Plans
RBSK	Rashtriya Bal Swasthya Karyakram
RCH	Reproductive and Child Health
RGJAY	Rajiv Gandhi Jeevandayee Arogya Yojana
RMNCHA	Reproductive, Maternal, Newborn, Child and Adolescent Health
RMP	Registered Medical Practitioner
ROP	Record of Proceedings
RSBY	Rashtriya Swasthya Bima Yojana
SC	Scheduled Caste
SDMC	School Development and Management Committees
SHG	Self Help Group
SN	Staff Nurse
SNCU	Special Neo-natal Care Units
SSA	Sarva Shiksha Abhiyan
ST	Scheduled Tribe
TA	Travel Allowance
TCS	Tata Consulting Services
ToR	Terms of Reference
UNICEF	United Nations International Children's Emergency Fund
UP	Uttar Pradesh
USA	United States of America

VHSC	Village Health and Sanitation Committees
VRW	Village Rehabilitation Worker
WHO	World Health Organization
WIFS	Weekly Iron and Folic Acid Supplementation

**2Ds covered under RBSK:**

List of Birth Defects and Developmental Delays	
Birth Defects	Neural Tube Defect
	Down's Syndrome
	Cleft Lip & Palate/Cleft Palate alone
	Club Foot/Talipes
	Developmental Dysplasia of Hip
	Congenital Cataract
	Congenital Deafness
	Congenital Heart Disease
	Retinopathy of Prematurity
Developmental Delays	Vision Impairment
	Hearing Impairment
	Neuro-Motor Impairment
	Motor Delay
	Cognitive Delay
	Language Delay
	Behaviour Disorder
	Learning Disorder
	Attention Deficit Hyperactivity Disorder

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The Formative Research Report covering the Knowledge, Attitudes, Beliefs and Practices (KABP) to develop the National Communication Framework for an ongoing Child Health Programme, *Rashtriya Bal Swasthya Karyakram*, was developed by Deloitte team in coordination with Ministry of Health and Family Welfare, Government of India, and with funding support and technical guidance from UNICEF. This has been a collaborative engagement and a participatory process.

We are grateful to the team from MoHFW – Dr. Ajay Khera (Deputy Commissioner, Child Health), Dr. Arun Singh (National Advisor to RBSK) and Mr. Premjith (National IEC Consultant, RBSK) who enriched this study with their active participation in meetings and field visits.

We sincerely thank the team members from UNICEF Delhi Office who provided valuable inputs and assisted Deloitte team in managing this study. This unique formative study covering 878 caregivers of children with 2Ds, 170 community members and 80 supply-side functionaries was led by Principal Investigators – Ms. Geeta Sharma and Dr. Pravin Khobragade from UNICEF. They were constantly engaged through the study and joined Deloitte team for field visits to Maharashtra, UP, Meghalaya, and Tripura.

We are immensely grateful to the technical inputs provided by our Communications Expert, Dr. Nilesh Chatterjee. We also wish to acknowledge the efforts of our research agency, Dexter Consultancy Pvt Ltd. Last but not the least, the credit goes to over 1100 respondents who provided their valuable time and shared their experiences, insights, and stories to make this report feasible.

The team members from different organizations who were engaged throughout are listed below:

MoHFW Team	UNICEF Team	Deloitte Team
Dr. Ajay Khera	Ms. Geeta Sharma	Ms. Anupama Joshi
Dr. Arun Singh	Dr. Pravin Khobragade	Ms. Lakshmi Gopalakrishnan
Mr. Premjith		Mr. Deepak Seharawat and Ms. Avani Venkateswaran

## About the Report

UNICEF engaged Deloitte India to conduct a Formative Study on Knowledge, Attitudes, Beliefs, and Practices (KAP) of caregivers of children with birth defects, and developmental delays. The findings from the formative study was used to design a National Communication Framework for RBSK.

Deloitte has developed this Report into two parts: This is Part 1 of the Report: '*Formative Research Report*'. It covers the analysis from the primary study covering caregivers of children with developmental delays and birth defects (2Ds), community-level members including mothers-in-law, head teachers, informal service providers, and members of formal/informal groups, and frontline workers. The analysis has been presented by each type of stakeholder – covering their knowledge, attitudes, beliefs, practices of caregivers of children with birth defects and developmental delays. Additionally, it covers the systemic and operational gaps in implementing RBSK, and capacity development needs of the supply-side functionaries.

'*National Communication Framework for RBSK*', part 2 of this Report is informed by the findings from Formative Research Report. It is presented as a separate report and covers situation analysis of 2Ds, implications for communication framework, barriers faced by caregivers of children with 2Ds, communication goals, and objectives, key audiences, communication approaches, implementation framework, and capacity development for supply-side functionaries.

# Executive Summary

## Introduction to RBSK

With a child population of over 400 million, India has the largest number of children between the ages of 0-18 years globally. India's child health indicators are a cause of concern, as India contributes 20% to global child deaths. The actual burden of birth defects and developmental delays is not known in India due to inadequate epidemiological information. Birth defects prevalence varies from 61 to 69.9 per 1000 live births.<sup>1</sup> With a large birth cohort of almost 26 million per year, India would account for the largest share of birth defects in the world, which translates to 1.7 million birth defects annually accounting for 9.6 per cent of all newborn deaths.<sup>2</sup> Further, developmental delays including disabilities are also a substantial cause of morbidity in early childhood, affecting around 10% of children. About 20% of babies discharged from Special Newborn Care Units (SNCUs) were found to be suffering from developmental delays or disabilities at a later age.<sup>3</sup> Developmental delays including disabilities in the first five years significantly hinder the growth potential of the child.

With a view to comprehensively address all child health conditions, including birth defects, and developmental delays, the Ministry of Health and Family Welfare launched the **Rashtriya Bal Swasthya Karyakram** in 2013 to provide targeted, comprehensive care to children aged 0–18 years. The programme covers screening, early intervention, management and treatment, including surgeries for the required health conditions, free of cost. Although it was initiated in 2013, the implementation of the programme has been staggered, with different States at different stages of implementation.

## Objectives of the Study

With limited epidemiological and social research data on children with birth defects, and developmental delays, the objective of this formative study was to improve the understanding of knowledge, attitudes, beliefs related to 2Ds, and health-seeking practices among caregivers of children with 2Ds, and social norms that influence decisions of caregivers. The study also documented key challenges and barriers facing the marginalised groups from accessing RBSK services. The study sought to interview supply functionaries to understand their skills, and incentives required to deliver services, and barriers, and biases faced by frontline workers, service providers and institutional-level stakeholders at state/district in delivering effective services under RBSK. The findings of the formative study was used to develop the **Social and Behavioural Communication Framework on RBSK**.

## Methodology

The study was set in a rural context, and was carried out across 8 High Priority Districts chosen across 5 States – Karnataka, Maharashtra, UP, Tripura and Meghalaya. Being a formative study with limited research and secondary data on the topic, the study adopted a qualitative approach to explore responses of primary caregivers of children with 2Ds covering all age groups – newborns (0-6 weeks), children 6 weeks up to 6 years of age, 6 years up to 18 years of age.

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<sup>1</sup> Estimates of the birth defects are conservative numbers due to constraints in diagnostic capability, poor health-related statistics, lack of birth defects surveillance and registries, reliance on hospital-based rather than population-based studies and systematic underestimation of the toll of birth defects

<sup>2</sup> March of Dimes Report 2006

<sup>3</sup> Operational Guidelines on RBSK, Ministry of Health and Family Welfare (2013)

The data collection methods included in-depth interviews with 878 caregivers, interviews and focus groups with over 170 community members including mothers-in-law, informal health providers (IPs), head teachers, key community members from the village (GP/SHG/SDMC members).

The study also included interviews with over 80 National, State, District, and Block level Health Department officials, other Department officials including WCD, Social Justice, and School Education. Systemic, and operational challenges, capacity development constraints including gaps in skills and motivation to ensure effective delivery of services under RBSK were covered.

## Findings from Primary Caregivers

The formative study included a total of 878 of caregivers of children who have been screened to have a birth defect or development delay, unscreened children suspected to have a 2D, apparently 'normal' children, and newborns. The study covered a diverse representation of rural population in terms of income, education, religion, and caste. Of all the caregivers interviewed, nearly 60% of the caregivers had a children with 2Ds, 33% of them had children identified with developmental delays, and 22% of them had children with birth defects. Congenital Heart Disease (CHDs) was the most common birth defect (25%), and language delay was the most common developmental delay (27%).

## Knowledge, Attitudes, Beliefs towards children with 2Ds and practices of caregivers of children with 2Ds

### Knowledge of health conditions of children with 2Ds and RBSK was found to be quite 'limited'

Caregivers' knowledge were unaware of the any technical or medical details of their child's condition. For children with visible birth defects and developmental delays, caregivers gave a vague explanation such as *'his legs are weak and he can't walk properly'* or *'brain is not developed'*, indicating limited understanding of the condition. 40% of caregivers of children with easily discernible birth defects were able to know of the condition at birth. Only 15% caregivers of children with developmental delays knew of their child having a condition at birth as developmental delays usually manifests itself during a later stage. With respect to awareness of RBSK, 55% of the caregivers indicated knowing about the programme. This was measured through their awareness of a team of doctors coming to the schools and Anganwadi centres to conduct a check-up for children.

### Overall positive stance towards children with 2Ds, or children with special needs (CWSN)

With absence of a scale to measure attitude towards 2Ds, caregivers' attitudes were measured through a vignette of a fictional caregiver, *'Kamla'* and her daughter *'Radha'* with a speech and hearing impairment. 87% respondents did not feel that the community members in the village would socially exclude caregivers like *'Kamla'*. 69% of the respondents felt that children with special needs such as *Radha* could be mocked at by other children, attributing it to the mischievousness and immaturity of children.

### Worry looms caregivers about children's future, communities and frontline workers lend support

Over 50% of caregivers' were beset with worry or depression when they found out about their child's condition, majority of the caregivers' worry originated from thinking about the future of their child, especially when the parents would no longer be around to take care of their children. Responding to a question on the response they received from community members and frontline workers, nearly 32% of them reported receiving encouragement to seek medical care for the affected child.

### Caregivers unable to discern between the cure vis-à-vis care approach for 2Ds

Caregivers are not be able to characterize between medical conditions associated with 2Ds, and are unable to distinguish between different interdisciplinary approaches of **care or cure** that may be possible

for a variety of conditions covered under RBSK. There is a general tendency to look at 'cure' for all types of 2Ds, often leading to disappointment, as many conditions require rehabilitative approaches.

#### Caregivers invested in the curative model of medical care and possess the 'right' set of beliefs

80% of caregivers believed in the power of medicine, indicating their child could be 'cured'. 55% of the caregivers attributed the cause of the condition to poor health seeking behaviors during pregnancy and childbirth. 25% of caregivers met did not associate any beliefs with their child's condition or were unable to articulate it during the interviews. Only 10% of the caregivers attributed their child's condition to God's wish, black magic, past deeds, or other inauspicious events that were outside their control.

#### Preference towards private sector with caregivers incurring high out-of-pocket expenditure

Caregivers had a higher preference to go to the private sector for the initial screening and diagnosis, especially in the case of visible birth defects. 35% of parents sought treatment at private sector and had incurred an average out-of-pocket expenditure of 45,000 INR. 16% of parents sought treatment at government health facilities, and only 7% of caregivers reported having tried alternative forms of therapy such as traditional healing, Ayurveda, among others.

#### Two most commonly faced barriers among caregivers of children with 2Ds include finance and transportation services

Financial considerations were a barrier both in routine care of the child at home, and to avail treatment for the child at a health facility. More than 50% caregivers pinpointed finance as their top barrier. 21% of caregivers reported that transportation was a barrier in reaching a health facility. 13% of caregivers identified lack of information regarding child's condition as another impediment to finding suitable treatment option.

#### Many factors can improve uptake of RBSK services, especially the evaluation and management

Facilitating factors were awareness of RBSK through MHTs and FLWs including information on 'free treatment', free transportation services, complementary health insurance programmes that also cover a few RBSK conditions, caregivers' determination and optimism to care for their child despite challenges, and stories of children with 2Ds in their community who had a positive experience with RBSK in the past.

### Findings from Other Stakeholders

With respect to KAP of informal service providers, 80% of the IPs were aware of and have had children with 2Ds come to them for treatment. However, many were unaware of RBSK and the services offered under it. They shared positive attitude towards children with 2Ds, and feel that these children could be treated with Western medicines. They had a range of beliefs regarding the child's condition, from myths and God's wish, to poor eating habits during pregnancy and improper care during childbirth. However, most of them reposed their faith in the medical system, especially for children requiring surgical interventions. Some providers also provide treatment in the form of herbal/Ayurvedic medicines, and sometimes in the form of religious chants and prayers. Whenever surgical interventions are imperative, typically they refer children to health facilities.

With regard to KAP of teachers, most of the teachers interviewed had a limited understanding of RBSK. However, many of them are aware of other state health insurance schemes and Sarva Shiksha Abhiyan (SSA's) Inclusive Education (IE) Programme. They showed compassion and care towards the children with special needs, by usually give them greater attention in the classrooms.

With respect to KAP of mothers-in-law, they are unaware of RBSK, and services offered under it. Like the caregivers/parents, they tend to be aware of their grandchild's condition when it is a visible birth defect or a prominent developmental delay. They tend to be distressed about the long-term care and future of the child. They displayed a range of beliefs including God's wish, fate, to poor antenatal care and inter-relation marriages. They exhibited a progressive attitude towards availing medical treatment for their

grandchildren with 2Ds. They also were proactive in choosing medical treatment over other forms of care. However, 3 out of 8 mothers-in-law expressed fear of surgery for their grandchildren.

With respect to KAP of formal/informal groups, they demonstrated knowledge of RBSK, including continuum of care. Their attitude ranged from supportive, and compassionate to discriminatory. Many of them are already playing the role of influencers, and instill positive behaviours in teachers and other school children towards children with 2Ds. They also felt that RBSK was beneficial for low-income families. They believed that these conditions were caused due to improper care during pregnancy and child birth, and hereditary causes. With respect to their practices, many of them are not actively engaged in the programme, however, expressed an interest in supporting and counseling caregivers on RBSK and other government programmes including health insurance.

### Key Findings from Institutional Stakeholders including Health and Other Departments

Interviews with the various officials at State/ District levels across five study states revealed that the degree of knowledge about basic programme details varies among the different stakeholders:

**Limited importance being accorded to RBSK among other health programmes:** With a multitude of programmes under National Health Mission, perceived low importance given to RBSK, emphasis on RBSK was rather inadequate. This was reinforced by the slow progress in training of service providers on RBSK, and delayed progress on effective implementation of all aspects of RBSK including a functional referral network.

**Poor availability of evaluation, and referral system and delays in setting-up DEICs:** Public health facilities still do not have the ability to perform evaluation and management/treatment of 2Ds, often compelling caregivers to go to private sector diagnostics. The huge out-of-pocket expenditure dissuades caregivers from seeking further referral and management services. Instead of experiencing the necessary care and free treatment as envisioned under RBSK, caregivers are often subjected to physical, psychological and financial stress.

**Slow progress on operationalizing DEICs:** is adversely affecting the successful implementation of evaluation and management services for children with 2Ds, subsequently reducing its uptake.

**Absence of mapping of secondary/tertiary services:** Officials from Health Department reported feeling constrained by their inability to act in the absence of Memorandum of Undertaking(s) with private sector/ government sector, medical colleges, religious charity-based hospitals, non-profit organisations. Further, lack of clarity on guidelines on mapping of secondary/tertiary care institutions for evaluation/management of 2Ds available makes it difficult to deliver evaluation services and free treatment/management.

**Weak convergence mechanisms:** Limited sensitization of officials in other departments at State/ District/ Block levels on RBSK has led to low involvement of officials in RBSK. Further, there are no institutionalised convergent mechanisms on how to leverage similar efforts being made by other Departments.

**Limited use of IEC/BCC funds:** IEC/ BCC activities are being limited to printing registers and referral cards. This is due to poor understanding of IEC/BCC among Department Officials, and their inability to understand the linkage between effective IEC/BCC and programme uptake among beneficiaries.

**Limited orientation on RBSK for institutional stakeholders and service providers:** Health Department Officials, medical officers concerned in public health facilities do not possess a sound understanding of RBSK, its objectives and its associated health conditions. This is due to the lack of orientation of the public health system functionaries.

**Absence of IPC and counseling skills for service providers including MOs, MHTs, FLWs:** In the absence of mapping of service available, limited clarity on their roles in RBSK, absence of training on IPC and counseling skills for service providers, especially the MHTs and FLWs, they are unable to clearly inform parents about the right course of action for the child, duration of the treatment, necessary procedures and the process involved. Lack of effective communication negatively impacts uptake of services under RBSK. Absence of caregiver education about '*care versus cure*' approach for different type of 2Ds, limited guidance on the personalised course of action required for each child with 2D, and poor knowledge about the condition among caregivers, dependence on a somewhat perceived unreliable medical system reinforces their mistrust in the public health system limiting further uptake of the programme.

## Policy Recommendations

**Introduce mapping of tertiary care services and strengthening network of tertiary care institutions including DEICs:** A clear mapping of services available across the State, neighbouring States including private sector, non-profit, government sector for all types of curative, rehabilitative, diagnostic services should be made available at each public health facility and with all MHTs, and programme officers of RBSK. Further, strong advocacy should be carried out with National/State Governments to expedite operationalization of DEICs so that caregivers are able to avail all services under a single umbrella instead of being sent from one facility to another.

**Provision of free diagnostics for the children screened to have 2Ds:** Provision of 'free' RBSK related diagnostics (e.g., 2D Echo) to be ensured through a variety of ways including functional DEICs, through tie-ups with private providers, or through NHM's Free Diagnostics Service Initiative at all public health facilities.

**Trainings for all service providers involved in RBSK:** All service providers across PHCs/CHCs/DHs, FLWs, and other Department Officials should be sensitized on the rationale and details of RBSK so as to meaningfully engage them in the programme.

**Multi-skilling of AYUSH doctors as key link workers for RBSK:** Since many long-term care services may take time to be rolled out at public health facilities and difficulty in finding trained psychologists because of the nature of specialization involved, MHTs could be potentially trained to become multi-skilled workers. Also, given the sensitive nature of health conditions being dealt with under RBSK, trainings should include interpersonal communication skills, and counseling skills for AYUSH doctors. Better performing AYUSH doctors could be recognized through promotion avenues including through Central Government Health Services (CGHS) AYUSH dispensaries or as DEIC managers. Provision of smartphone-based application or a database with an electronic record of all children can be made for tracking each child screened. This could enhance their motivation in the programme and create a sense of purpose beyond screening children.

**Dedicated helpdesks and kiosks for RBSK beneficiaries at public health facilities:** Setting-up of a dedicated RBSK kiosks/helpdesks at the referral facilities and holding special RBSK-specific evaluation on specific calendar dates (once a week) may be implemented to address navigation-related barriers at the facility-level.

**Re-visiting daily screening targets for MHTs:** Daily targets have been found to be too ambitious, and the emphasis on targets is compromising the quality of the screening. These targets must be appropriately modified; depending on the terrain and population of children (0-18 years), to ensure optimal screening services.

**Enable transportation services for RBSK beneficiaries:** Appropriate measures need to be taken to address the transport barrier for caregivers. Transportation facility once a month for a group of RBSK beneficiaries/caregivers may be explored.

**Set-up convergence mechanisms and partnerships with non-profits, religious charities, and private sector:** Convergence mechanisms should be set-up between Health and other related Departments (including Women and Child Development, Human Resource Development, Social Justice and Empowerment) in the form of regular meetings with designated officials at the state, district, and block levels and through formal training on RBSK to officials/frontline workers of other Departments. Mapping of rehabilitative/tertiary care services should include services and resources made available by other Departments such as Social Justice, private sector hospital network, and non-profits, civil society organizations, and religious charities working for caregivers and their children with special needs.



# Chapter 1: Introduction

## Status of Child Health in India

With a child population (up to 18 years of age) of over 400 million, India has the largest number of children in the world. However, child health indicators in India continue to be alarming. A significant number of children die every year due to preventable diseases and infections, with four diseases (respiratory infections, diarrheal diseases, other infectious and parasitic diseases, and malaria) contributing to half of under five deaths in the country.<sup>4</sup>

Further, with estimated 26 million births every year, India's contribution to global child deaths is a significant 20%<sup>5</sup>, under five child mortality is 1.27 million children per year, of which 81%<sup>6</sup> takes place within one year of age.

The table below provides key child mortality indicators for India and the focus states for this study.

**Table 1: Key Child Mortality Indicators<sup>7</sup>**

	Neonatal Mortality Rate	Infant Mortality Rate	Under Five Mortality Rate
Karnataka	22	31	35
Maharashtra	17	24	26
Meghalaya	-	47	-
Tripura	-	26	-
Uttar Pradesh	35	50	64
<b>India</b>	<b>28</b>	<b>40</b>	<b>49</b>

## Initiatives by government in Improving Child Health in India

The Government of India has introduced several initiatives and programmes over the years to address the country's poor child health and survival status over the years. The exhibit below highlights the key interventions among these.

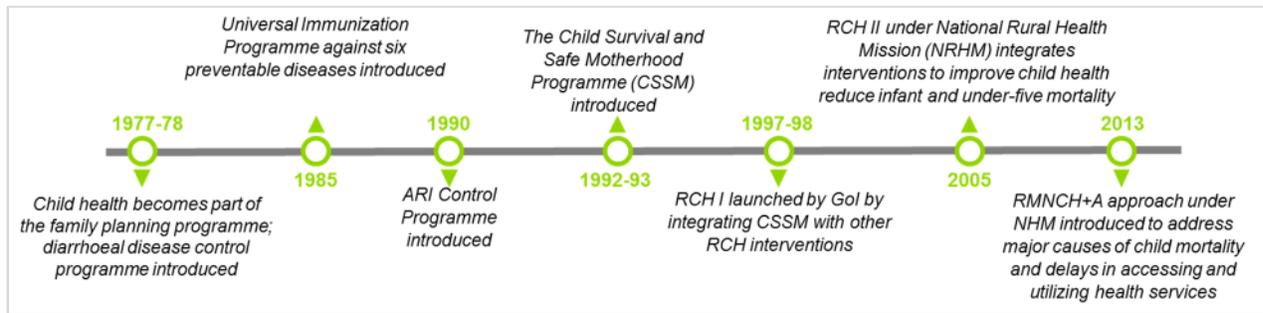
<sup>4</sup> The Situation of Children in India – A Profile, UNICEF

<sup>5</sup> The Situation of Children in India – A Profile, UNICEF

<sup>6</sup> Child Health Background, National Health Mission

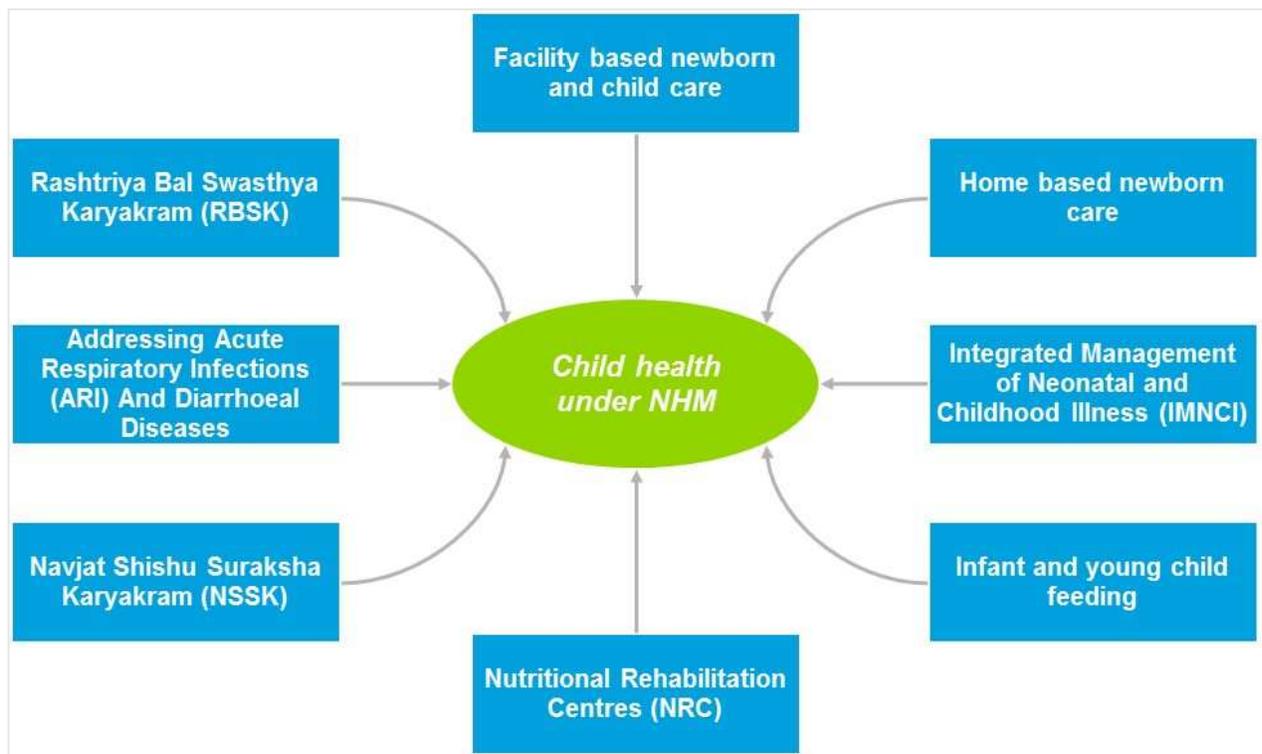
<sup>7</sup> Sample Registration System (SRS) 2013

**Exhibit 1: Evolution of Child Health Programmes in India**



The National Health Mission’s child health programme addresses child health and survival using a Continuum of Care approach, providing health interventions across a child’s lifecycle. The programme also aims to provide seamless healthcare services through care at home, community outreach, and at health facilities. The programme follows a multi-pronged approach, with its key tenets summarized in the exhibit below.

**Exhibit 2: Child Health Interventions under NHM**



## Overview of RBSK

### 4Ds among children in India

Defects at birth, Diseases, Deficiencies and Developmental Delays including Disabilities (4Ds) pose a significant threat to India's child population. The magnitude of these ailments is summarized in the exhibit below. A lack of a proper surveillance system limits the ability to capture the exact magnitude of 4Ds among children.

**Exhibit 3: 4Ds among children in India<sup>8</sup>**

<b>Defects at birth</b>	<ul style="list-style-type: none"> <li>▪ Out of every 100 babies born annually, 6 to 7 are estimated to have a birth defect</li> <li>▪ Birth defects account for <b>~7% of all newborn deaths</b></li> </ul>
<b>Diseases</b>	<ul style="list-style-type: none"> <li>▪ Common diseases among children include dental caries, rheumatic heart disease, reactive airways diseases, etc.</li> <li>▪ <b>Prevalence of dental caries is ~50-60%</b> among Indian school children; of <b>rheumatic heart disease is 1.5 per 1,000</b> (among school children in the age group of 5-9 years) and <b>0.13 to 1.1 per 1,000</b> (among 10-14 years)</li> </ul>
<b>Deficiencies</b>	<ul style="list-style-type: none"> <li>▪ <b>Nutritional deficiencies</b> among pre-school children range from <b>4-70%</b></li> <li>▪ Among under five children: anemia prevalence estimated to be 70%, 48% are chronically malnourished</li> </ul>
<b>Development delays</b>	<ul style="list-style-type: none"> <li>▪ <b>Development delays afflict an estimated 10% of children</b>, which can lead to permanent disabilities if not treated in a timely manner</li> <li>▪ ~20% of babies discharged from SNCUs found to suffer from developmental delays or disabilities at a later age</li> </ul>

### Programme Details

**Rashtriya Bal Swasthya Karyakram (RBSK)** provides early screening, detection, management and treatment including surgeries for the required health conditions, free of cost. The Ministry of Health and Family Welfare launched RBSK in 2013, to provide targeted, comprehensive care to children aged 0-18 years. This is one of the unique programmes in the world aimed at early screening of and early intervention for 4Ds among children to minimise disability in children. RBSK shifts away from a rehabilitative approach towards a more public health approach to reduce risk factors and early identification of children with 4Ds to prevent the onset of disability. Early screening will benefit in reducing mortality and morbidity, improving survival and nutrition outcomes, reduction of malnutrition related deaths, enhancement of cognitive development and school performance, educational attainment, overall improvement of quality of life of children.

The programme targets children from birth until 18 years of age, and programme aims to cover estimated 27 crore children in a phased manner, comprising of:<sup>9</sup>

- 2 crore children aged up to 6 weeks
- 8 crore pre-school children in rural areas and urban slums, aged 6 weeks to 6 years, and

<sup>8</sup> March of Dimes Report, 2006; RBSK Operational Guidelines, February 2013

<sup>9</sup> Operational Guidelines: Rashtriya Bal Swasthya Karyakram (RBSK)

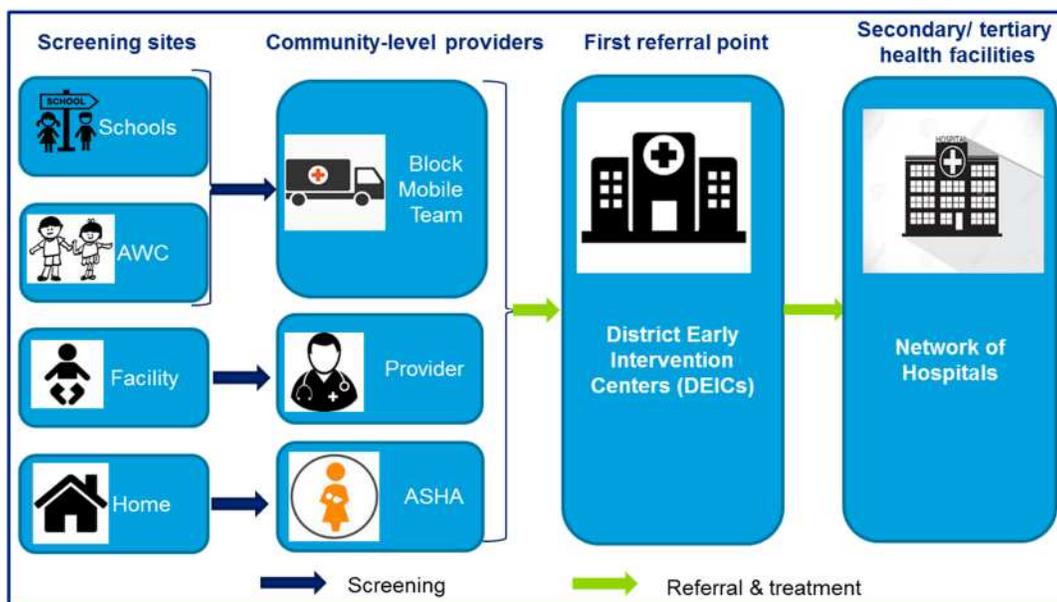
- 17 crore children enrolled in government and government aided schools, aged 6 to 18 years

Per the guidelines of this programme, screening of children up to 6 weeks of age is conducted initially at delivery points by medical officers, staff nurses, and ANMs, and subsequently at home by ASHAs as part of Home Based New-born Care (HBNC). Screening of children aged 6 weeks to 6 years takes place at Anganwadi centres at least twice a year, and of children aged 6 to 18 years at school. Screening for children at both these locations is conducted by mobile health teams. These mobile health teams consist of two AYUSH doctors (one male and one female), one ANM/Staff Nurse and one pharmacist with computer skills.

Children that have been screened and diagnosed with a health condition are referred to early intervention centres that have been set up at district hospitals (District Early Intervention Centres- DEICs) or to other secondary/tertiary facilities wherever DEICs are yet to be set up. These DEICs are the first referral point for further investigation, treatment and management and provide referral linkages to designated secondary/ tertiary health facilities.

A schematic representation of screening and care delivery under RBSK has been depicted in the exhibit below:

**Exhibit 4: Service Delivery under RBSK**



### Progress under RBSK

The utilisation of the programme is growing at a steady pace, the target number of children to be screened in 2014-15 was 32.81 crore<sup>10</sup>; 11.52 crore children (35% of the target) were screened during the year. 1.15 Crore children were identified with 4Ds, of which 0.48 crore (41%) were referred, and only 46% of those referred availed secondary/ tertiary care<sup>11</sup>. The proportion of children referred that availed a higher level of care has improved in 2014-15 (46% as compared to 25% in 2013-14<sup>12</sup>), but remains low.

<sup>10</sup> Note: This number is higher than the estimated cohort of children in the age group 0-18 years (27 crore)

<sup>11</sup> RBSK Division Report, 2014-15

<sup>12</sup> Annual Report of Department of Health & Family Welfare, 2014-15

Further, from programme delivery infrastructure standpoint, 11,008 mobile health teams and 306 DEICs have been approved. ~9660 (88%) mobile health teams are in position and 92 (30%) DEICs are operational.<sup>13</sup>

The expenditure utilisation under the program for 2014-15 is INR 529 crore, while financial allocation is INR 1,384 crore<sup>14</sup>. This translates into expenditure utilisation of 38%. There are large differences for expenditure utilization among states, Uttar Pradesh, for example, has an expenditure utilisation under RBSK of 75%, while that of Meghalaya is as low as 8%. Tripura, Maharashtra, and Karnataka have expenditure utilisation figures in between these two extremes, of 17%, 47% and 51%, respectively.

Further, there is large variance in coverage and progress of the program among different states. The table below summarises the performance of the five states included in this study:

**Table 2: State-specific performance under RBSK, 2014-15**<sup>15</sup>

	Target children for screening (in lakhs)	Children screened as % of target	Children referred as % of children identified with 4Ds	Children availing higher level of care as % of children referred
<b>Karnataka</b>	132	70%	100%	79%
<b>Maharashtra</b>	271	71%	12%	105% <sup>16</sup>
<b>Meghalaya</b>	11	26%	8%	98%
<b>Tripura</b>	12	12%	71%	135% <sup>17</sup>
<b>Uttar Pradesh</b>	517	35%	28%	76%

### Need for the study

While the programme exists to cater to children with 2Ds, India does not have a surveillance system to capture the magnitude of birth defects and developmental delays. In addition to limited surveillance/epidemiological data, social research studies on this topic with the different types of birth defects and developmental delays is very scarce. Consequently, very little is known about the perceptions, knowledge, attitudes and practices of caregivers of children with 2Ds and that of the larger community including health system functionaries.

While there are other health programmes in place to address the diseases and deficiencies covered under RBSK, interventions exist to address birth defects and development delays including disabilities (2Ds). As a result, a formative study focusing on birth defects and development delays is essential at this juncture, to address this gap and build evidence on the social norms, knowledge, attitudes, practices and health-seeking behaviours, and barriers of caregivers of children with 2Ds and community members. As

<sup>13</sup> Annual Report of Department of Health & Family Welfare, 2015-16; RBSK Division Report, 2015-16

<sup>14</sup> RBSK Division Report, 2014-15

<sup>15</sup> RBSK Division Report, 2014-15

<sup>16</sup> No explanation was provided by State Programme Officer, RBSK during Maharashtra Visit

<sup>17</sup> No explanation was provided by State Programme Officer, RBSK during Tripura Visit

indicated earlier, RBSK implementation has been quite slow and different states are in a different stages of implementation. This formative study was also meant to provide inputs into systemic and operational challenges that are impeding progress of the programme.

The perspectives collected will be used to inform the development of a communication framework aimed at targeting and overcoming attitudinal and behavioural challenges. The study aims to offer clarity on the target audiences, the themes for messages that need to be tailored for social change, and different modes of communication that would be effective in reaching out to the target population. This kind of targeted communication framework is expected to achieve two-fold benefits – (1) sensitization of communities on the benefits of early diagnoses and services of the programme and (2) influence their readiness to access services under RBSK and improve utilization of services under RBSK.



### Objectives

- The main objectives of the study were to explore knowledge, attitudes, beliefs, and practices of community members and caregivers of children with 2Ds, identify barriers that prevent caregivers from seeking formal health system, enablers that are currently or could in the future encourage caregivers to get their screened children evaluated, and seek appropriate interventions, as required. The findings from this study are used to inform the Social Behavioural Change Communication (SBCC) Framework to further improve utilisation of services under RBSK for all children in the age group 0-18 years and for children screened to have 2Ds.

### Study States

- The study was set in a rural context, and was carried out across 8 High Priority Districts chosen across 5 States – Karnataka, Maharashtra, UP, Tripura and Meghalaya. Being a formative study with limited research on the topic, the study adopted a qualitative approach to explore responses from primary caregivers of children with 2Ds covering all age groups – newborns (0-6 weeks), children 6 weeks up to 6 years of age, 6 years up to 18 years of age.

### Data Collection Methods

- The data collection methods included in-depth interviews with 878 caregivers of children screened to have 2Ds, and caregivers of children with normal children, and focus groups with over 170 community members including mothers-in-law, informal health providers (IPs), head teachers, key community members from the village (GP/SHG/SDMC members).
- The team also held interviews with over 80 National, State, District, and Block level Health Department officials, other Department officials including WCD, Social Justice, and School Education were also covered at National, State, District, and Block level. Systemic, and operational challenges for service delivery, capacity development constraints including gaps in skills and motivation were covered.

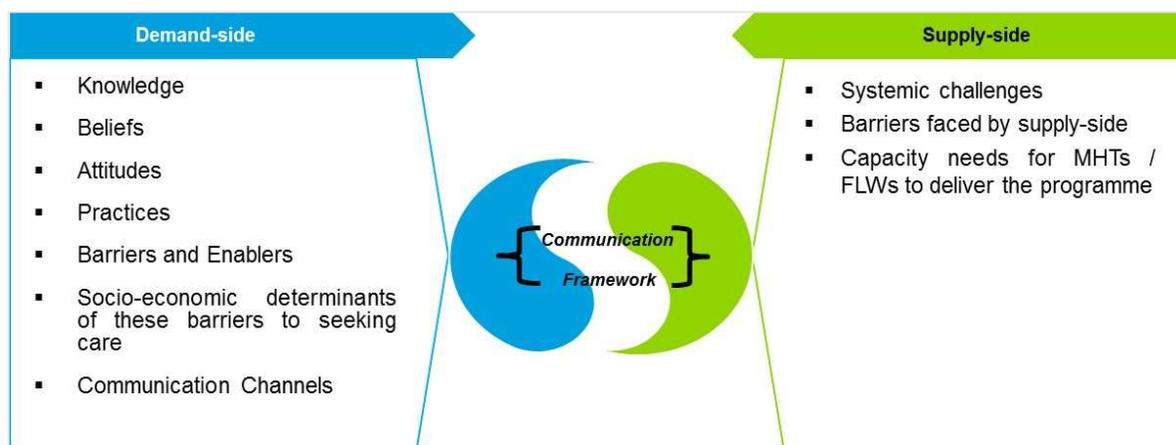
### Objectives of the Study

The objective of this formative study is to understand key perceptions of caregivers of children with 2Ds, identify barriers that prevent, and enablers that encourage early screening for all children and promote evaluation and interventions for children with 2Ds. The evidence-based findings from this study will be used to craft a Social and Behavioural Change Communication Framework to improve utilization of RBSK services for all children, especially children screened to have 2Ds.

# Chapter 2: Methods

In particular, the study has sought to understand the following from caregivers of children with 2Ds and supply-side functionaries thereby encompassing both the demand-side and supply-side dimensions:

**Exhibit 5: Dimensions of the study**



## Desk Review

The team from Deloitte reviewed various relevant documents, RBSK operational guidelines, RBSK Division reports, Government orders / circulars and State PIPs / ROPs. These documents enhanced understanding of the programme objectives and status of the programme, and provided the basis for the preparation of the inception report and study tools.

The team also attended the National Review Meeting on RBSK that was held in Delhi in November 23-24, 2015, which provided valuable insights into programme implementation and challenges being faced by the different States. Following the National RBSK Review Meeting, Andhra Pradesh was replaced by Karnataka as one of the study States, in agreement with UNICEF and MoHFW. This was done because RBSK teams were not recruited in Andhra Pradesh by November 2015; Karnataka served as a representative southern State instead.

A brief research was then conducted to understand the context of the chosen States-Karnataka, Maharashtra, UP, Tripura and Meghalaya and the respective HPDs chosen in these states by using survey data such as Census, District Level Household Survey, Annual Health Survey and Sample Registration Survey. This included review of indicators including population of SC/ST, female literacy rate, per capita income, health indicators such as institutional deliveries, child and maternal mortality among others.

## Literature Review

In order to design the study tools and to get a preliminary understanding of knowledge, attitudes, beliefs, practices, and barriers faced by children or caregivers of children with developmental delays and birth defects, articles on similar studies published from India and internationally were reviewed. The team found very few studies covering Knowledge Attitudes Practices (KAP) of caregivers pertaining to children with birth defects and/or developmental delays in India in the public domain.

A qualitative study<sup>18</sup> conducted in a rural village in UP covering 10 caregivers of children with intellectual disabilities found that these children were forced to live in with a poor quality of life because of cognitive, structural and financial barriers they face in accessing health care. Cognitive barriers include caregivers being unable to identify the complex needs of their children and poor information on government financial aid. Structural and financial barriers encompassed poor availability of healthcare providers and contributed to poor access to specialists. Another study<sup>19</sup> with 32 parents of children with developmental disabilities including cerebral palsy, mental retardation, and seizure disorder among others indicated both physician-related and parent-related barriers in dealing with children with developmental disabilities. Physician-related barriers were identified as lack of skills and understanding of children with developmental disabilities, lack of knowledge and resources, lack of specialist back-up services, and communication difficulties with regard to conveying bad news to clients. Parent-related barriers were financial constraints, delay in accepting the diagnosis, and prevalent myths, beliefs and stigma pertaining to disability. The teachers viewed children with special needs as an additional responsibility, and were also apprehensive about the attitudes and interaction of other children at school with children with disabilities. Another study identified parental stress in dealing with children with disabilities in India in an urban context, indicating that such families received little support from informal family resources.<sup>20</sup>

As indicated in the literature review, very few studies have been done to understand barriers faced by caregivers of children with developmental disability, intellectual disability, autism, etc. These studies were conducted in an urban setting, further limiting the ability to understand the plight of such children and their caregivers in rural areas. Since RBSK is in a nascent stage, team also did not find any study related to children with birth defects and/or developmental delays. Lack of data is further corroborated by the *World Disability Report (WHO, 2011)* that placed identification of barriers in mainstream healthcare, and strategies for overcoming barriers as one of the top research priorities for people with disabilities.

This context of limited data further reinforces the imperativeness to understand knowledge, attitudes, beliefs, barriers, and practices of families with children with defects, developmental delays including disabilities. A salient feature of this comprehensive formative study among caregivers of children with 2Ds is to inform the design of a social and behavioural change communication framework for an ongoing Child Health and Screening Programme (RBSK) under National Health Mission. The implementation of the social and behavioural change communication is expected to improve the utilisation of RBSK services.

## Formative Research

This formative study covered primary interactions with a variety of stakeholders. This included institutional stakeholders at the national, state, district and block levels, community members (including teachers, formal and informal health service providers, other community groups such as SHGs etc.), caregivers of children screened to have any of the 2Ds under RBSK, and caregivers of unscreened children including newborns. This chapter entails the study tools, sampling design, and stakeholders met during the course of the study.

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<sup>18</sup> Varghese J et al. Barriers in health care access faced by children with intellectual disabilities living in rural Uttar Pradesh, *Journal of Social Inclusion*, 6(1), 2015

<sup>19</sup> George, C. et al., Barriers to Early Diagnosis, Intervention and Social Integration of Children with Developmental Disabilities, *Disability, CBR, and Inclusive Development(DCID)*, 2014

<sup>20</sup> Gupta, V. Parental Stress in Raising a Child with Disabilities in India, *Disability, CBR, and Inclusive Development(DCID)*, 2012

## Study Tools

For each type of stakeholder and depending on type of interview, interview guides and focus group discussion guides were prepared mostly comprising semi-structured questions and structured questions to capture socio-economic details. The tools were developed in English and translated into Marathi, Kannada, Khasi, Bengali and Hindi to suit the local language in each of the study states. All the study tools were discussed with client counterpart teams from UNICEF and MoHFW. All the study tools were back translated from local languages into English to ensure that essence of the questions were not lost in translation.

**Table 3: Stakeholders interviewed and themes covered for each stakeholder category**

Stakeholder	Type of Interview	Type of Tool	Themes Covered in the Study Tool
<b>SUPPLY-SIDE</b>			
<b>RBSK officials at the Centre/ State/ District/ Block</b>	Face-to-face Interview	Interview guide with open-ended questions	Programme overview, HR recruitment and training, convergence Mechanisms with other Departments/ Ministries, infrastructure set-up such as DEICs and operationalization of DEICs, mobility for MHTs, implementation and scale-up of RBSK, good practices/ innovations, and challenges
<b>IEC Officials at Health Department at Centre/ State</b>	Face-to-face Interview	Interview guide with open-ended questions	Understanding of IEC, SBCC, among IEC officials, funding RBSK-IEC activities, RBSK-IEC activities
<b>Other Department Officials associated with RBSK (MHRD, MWCD, MSJE) at the State / District/ Block</b>	Face-to-face Interview	Interview guide with open-ended questions	Awareness of RBSK, mechanisms for coordination and planning at different levels – state, district, block and village, challenges in coordination, other programmes that complement RBSK
<b>Mobile Health Teams</b>	Focus Group Discussion	FGD guide with open-ended questions	Knowledge of RBSK, its importance, community mobilization, skills and motivation required to deliver the programme, key perceptions, social norms, and societal attitudes towards children with 2Ds, barriers for caregivers with children with 2Ds, communication channels to reach out to caregivers
<b>Frontline Workers (ASHAs, AWWs, and ANMs)</b>	Focus Group Discussion	FGD guide with open-ended questions	Knowledge of RBSK, clarity of roles amongst frontline workers, involvement of ASHAs, community mobilization, key perceptions, social norms, and societal attitudes on disabilities, developmental delays, skills and motivations required to deliver the programme, communication channels to reach out to caregivers
<b>DEMAND-SIDE</b>			
<b>Head Teachers</b>	Face-to-face interview	Interview guide with open-ended questions	Knowledge, attitudes, beliefs, practices among school teachers towards children with 2Ds and disabilities in general, perceived barriers faced by parents of children with 2Ds and disabilities in general, primary decision-makers for children with 2Ds, and awareness of Government initiatives for children with disabilities including SSA's Inclusive Education (IE), RBSK among others, communication channels to reach out to

Stakeholder	Type of Interview	Type of Tool	Themes Covered in the Study Tool
			parents, interaction and experiences with health systems, health-seeking practices of communities
<b>Informal Health Service Providers</b>	Face-to-face interview	Interview guide with open-ended questions	Background and practices of the informal health service providers, type of ailments for which service is offered, knowledge, attitudes, beliefs and practices of caregivers of children with 2Ds, health-seeking practices of communities, barriers and enablers for the parents, knowledge of RBSK, communication channels
<b>Mothers-in-law(i.e., Grandmothers whose grandchild has been screened to have any of the 2Ds)</b>	Face-to-face interview	Interview guide with open-ended questions	Background characteristics of mother-in-law, knowledge of condition of the child with 2D, attitudes towards children with 2D, perceptions of community members towards children with 2D, response of health system functionaries towards children with 2Ds, barriers to accessing care,
<b>Caregivers</b>	Face-to-face interview	Semi-structured interview guide with a few close-ended questions and largely open-ended questions with probes	Socio-demographic characteristics of family, perceptions of caregivers of children who have been screened and are found to be having 2Ds, response and support from family, community and health systems, knowledge, attitudes, beliefs and practices towards children with 2Ds, health-seeking behaviors and utilization of government health services, knowledge of RBSK, experience with frontline workers, exposure to and use of communication channels
<b>Formal and Informal Groups (SDMC members, Panchayat members, SHG members)</b>	Focus Group Discussion	FGD guide with open-ended questions	Key perceptions, social norms, and societal attitudes on disabilities, developmental delays, barriers for caregivers of children with 2Ds, , knowledge of RBSK, role of these groups including Gram Panchayats, Self-Help Groups, SDMC, VHSNC, etc., availability of and access to health providers and satisfaction with government health system

### Pre-test of Study Tools

The pre-test of the caregivers study tools and focus group discussion guide for MHTs was conducted in a DEIC in Gurgaon, Haryana. During the pre-test, the Deloitte team met with Civil Surgeon of the General Hospital in Gurgaon, DEIC Manager, 5 AYUSH doctors from Mobile Health Teams and 7 caregivers of children with 2Ds.

The key insights during the pre-test included:

- **Reduction in length of the interview guide:** The time taken in average then was over 70 minutes leading to a lot of respondent fatigue, decreasing the quality of responses. Given the sensitivities involved in dealing with children with either of the 2Ds, the team sought to remove the repetitive questions that eventually was not leading to improvement in the depth of responses.
- **Testing the efficacy of using a vignette:** The story of a fictional caregiver ('Kamla') with a child with a 2D to understand caregiver and community perceptions and norms, based on the responses of the caregiver to the story. This method was found to be successful in ascertaining social norms, and was especially useful in understanding various social issues and nuances, such as the role of the mother-in-law in determining health seeking behaviors and how the gender of the child influences these community perceptions. Statements following the vignette were refined to reduce usage of strong 'emotional language'.
- **Addition of a recall time frame:** Where feasible, questions with ambiguous choices such as '*how often*' was replaced with 'in the past 3 months, how many times did you interact with health workers (*weekly, monthly, quarterly, etc.*)'. Difficult recall questions were also avoided by keeping a recall time frame of 3 months in all questions, where necessary.
- **Placement of questions:** Question placement was carefully observed during the pre-test as it could potentially impact the quality of the data collected. Close-ended questions were shifted towards the end of the tool by allowing the respondent to initially think through about their experiences with the child and share their stories in the open-ended questions.
- **Addition of non-response choices:** Wherever applicable, non-response choices such as 'don't know', 'not applicable', etc. was added to account for unwillingness to answer or inability to comment/ answer questions.
- **Addition of a summary sheet:** Since a lot of qualitative information is being collected through open-ended questions, a top sheet / summary sheet was added for investigators to write down their key observations post the interview. This is recognized as one of the good practices in most qualitative interviews.

A detailed pre-test report with the exact changes made to the caregivers interview guides and focus group discussion guide for MHT was submitted to UNICEF in December 2015.

## Sampling Design

The study spanned five states - Maharashtra, Karnataka, Uttar Pradesh, Tripura and Meghalaya, covering two 'High Priority Districts' (HPDs<sup>21</sup>) each in Maharashtra, Karnataka, Uttar Pradesh, and one HPD each in Tripura and Meghalaya. Deloitte followed a 3-step approach for selection of HPDs for the study:

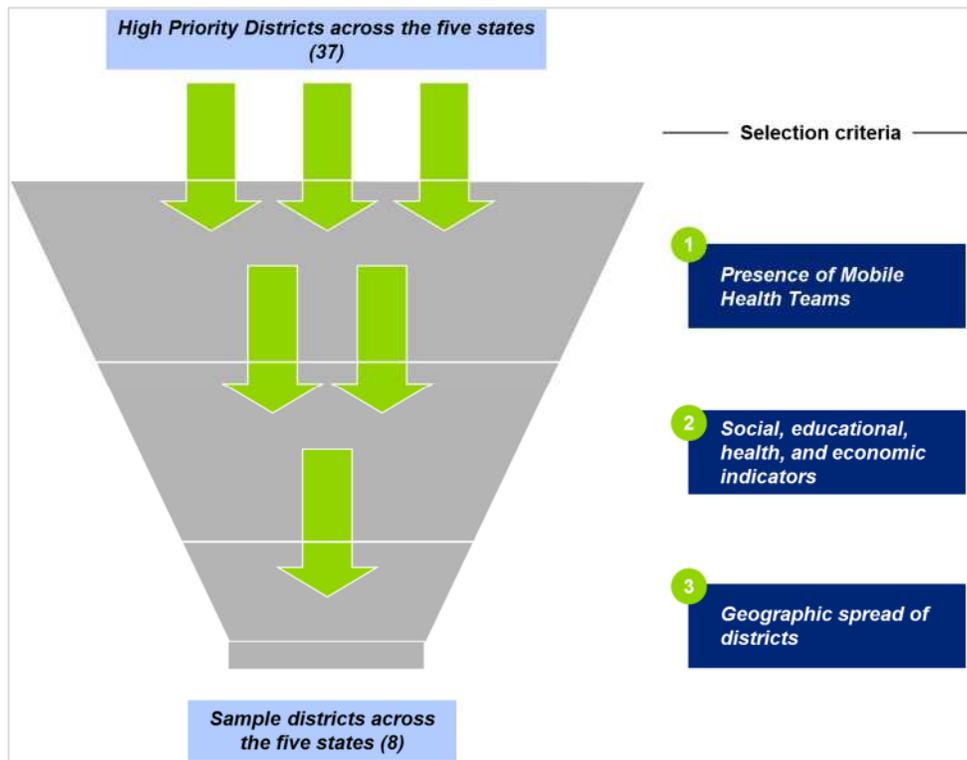
- Since the study was focused on improving utilization of RBSK, only those HPDs with functioning RBSK Mobile Health Teams (MHTs) were chosen. A functioning RBSK Mobile Health Team was defined as those with at least one male or female AYUSH doctor conducting screening activities for at least three months prior to the study;

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<sup>21</sup> Bottom 25% of the districts in every State according to the ranking of districts based on composite health index have been chosen as HPDs by the Ministry of Health and Family Welfare. All Left Wing Affected (LWE) districts and districts with majority tribal population, whose composite health index is below 50% are also categorized as HPDs.

- Next, each of the sampled HPDs were evaluated on a range of demographic, social, economic, and health parameters. These parameters were selected as illustrative indicators to ascertain the performance of the district. The parameters considered for each district were:
  - Representation of marginalized communities through % SC/ST population
  - Female Literacy Rate
  - Religious diversity through % Non-Hindu population
  - Per Capita Income (State)/ Per Capita Net District Domestic Product
  - % Institutional deliveries
  - % Disabled population
  - Infant Mortality Rate
  - Maternal Mortality Rate
  - Sex Ratio
- Using the parameters mentioned above, a three-point scale based on percentiles was used to comparatively grade districts, with negative parameters using a reverse scale. Using this scale, a cumulative score was calculated for each district. To ensure maximum divergence, sample districts were chosen from the highest and lowest scores for each state.
- As a final step, geographic spread of districts was used as a criteria for sampling, to avoid selection of adjoining districts in any state to the extent possible.

**Exhibit 6: Selection of Districts**



The map below shows the HPDs chosen for the study in the five states, based on the methodology described previously. As Tripura had only one HPD (Dhalai), it was chosen as the sample district for the State.

**Exhibit 7: Districts chosen across study states**

The final list of districts chosen was finalized in discussion with UNICEF and MoHFW. Only in Maharashtra, the adjoining districts of Aurangabad and Jalna were chosen as Jalna had a functional DEIC (District Early Intervention Centre). It was decided that it would be crucial to understand the parents' experiences of evaluation and treatment of children at the DEIC, in order to get a holistic understanding of caregivers' experience across the treatment continuum.

**Selection of Blocks**

Two blocks were chosen in each district and the blocks have been chosen based on the following criteria:

- One block with high-risk category population (with maximum population of marginalized populations such as SC/ST) and one block with low-risk category population (with lowest proportion of marginalized populations such as SC/ST)
- Geographic spread of blocks within the district
- Input were sought from district-level health officials

The list of blocks chosen within each district is provided in the table below:

**Table 4: Blocks chosen under each district**

State	District	Block 1	Block 2
<b>Karnataka</b>	Kalaburagi	Aland	Afzalpur
	Raichur	Devadurga	Sindhanur
<b>Maharashtra</b>	Aurangabad	Khultabad	Sillod
	Jalna	Bhokardan	Ambad
<b>Uttar Pradesh</b>	Barabanki	Dewa	Fatehpur
	Etah	Awagarh	Jaithra

State	District	Block 1	Block 2
Meghalaya	West Khasi Hills	Mairang	Mawthadraishan
Tripura	Dhalai	Ambassa	Gandacherra

### Stakeholders Interviewed

The number of stakeholders that were to be met as per Terms of Reference and actually met during the course of the study is provided in the following table:

**Table 5: Stakeholders interviewed for the study**

Level	Key Stakeholder Groups	No. / unit to be covered	Total sample to be covered	Total Sample covered
<b><i>In-depth Interviews</i></b>				
<b>National</b>	<ul style="list-style-type: none"> <li>▪ RBSK Officers</li> </ul>	-	2-3	3
<b>State</b>	<ul style="list-style-type: none"> <li>▪ State Health Secretary</li> <li>▪ NHM Mission Director/ Jt. Director (RCH)</li> <li>▪ State Programme Officer, RBSK</li> <li>▪ State Level ICDS Officer, DWCD</li> <li>▪ State Level SSA Officer, Department of Education</li> <li>▪ State Level Social Justice and Empowerment Officer</li> <li>▪ State Level IEC Officer</li> <li>▪ UNICEF- RMNCH Consultant</li> </ul>	4-5	20	20
<b>District</b>	<ul style="list-style-type: none"> <li>▪ District Collector/District Magistrate</li> <li>▪ Chief Medical Officer / District Health Officer</li> <li>▪ District Programme Officer, RBSK</li> <li>▪ DEIC manager/ relevant staff</li> <li>▪ Child Development Project Officers</li> <li>▪ District Education Officer</li> <li>▪ District Social Justice/ Disability Affairs Officer</li> <li>▪ District Community Mobilizer</li> </ul>	2-3 per district	16-24 For 8 districts	40 For 8 districts
	<ul style="list-style-type: none"> <li>▪ School Teacher/Head Teacher</li> <li>▪ Informal Health Service Provider</li> <li>▪ Mothers-in-law/Female family members</li> </ul>	2-3 per district	16-24 For 8 districts	24 For 8 districts
<b>Block</b>	<ul style="list-style-type: none"> <li>▪ Block Health Officer</li> <li>▪ ICDS supervisors</li> <li>▪ SSA official at block</li> <li>▪ Block Community Mobilizer</li> </ul>	2-3 per district*	16-24 For 8 districts	24 For 8 districts
<b>Community</b>	<ul style="list-style-type: none"> <li>▪ Caregivers of newborns</li> </ul>	15 per block	240 For 16 blocks	211 For 16 blocks
	<ul style="list-style-type: none"> <li>▪ Caregivers of children (6 weeks - 6 years) in AWCs</li> </ul>	15 per block	240 For 16 blocks	210 For 16 blocks
	<ul style="list-style-type: none"> <li>▪ Caregivers of children(6 -18 years) in Govt. Schools/Aided Schools</li> </ul>	15 per block	240 For 16 blocks	295 For 16 blocks
	<ul style="list-style-type: none"> <li>▪ Caregivers of children (0-18 years)</li> </ul>	10 per block	160 For 16 blocks	160 For 16 blocks
<b>Total In-Depth Interviews</b>		<b>-950-975</b>		<b>987</b>
<b><i>Focus Group Discussions</i></b>				

Level	Key Stakeholder Groups	No. / unit to be covered	Total sample to be covered	Total Sample covered
District	▪ Mixed groups of ANMs, AWWs, ASHAs	1 per district	8 FGDs For 8 districts	8 For 8 districts
	▪ Medical Officers (AYUSH doctors) of Mobile Health Teams	1 per district	8 FGDs For 8 districts	8 For 8 districts
	▪ Formal and informal group village members (SHGs/GP members, and SDMC members)	1 per district	8 FGDs For 8 districts	8 For 8 districts
<b>Total FGDs</b>				<b>24 FGDs across 8 districts with a total of 150 participants</b>
<b>Grand Total for 5 states (Total In-depth Interviews + Total Focus Group Discussions)</b>				<b>1137</b>

## Data Collection

As mentioned previously, data collection methods included:

- **Interviews** with government officials including state, district and block-level officials
- **In-depth interviews (IDIs)** with community members including caregivers of children with birth defects and developmental delays
- **Focus group discussions (FGDs)** with frontline workers (Anganwadi workers, ASHA workers, and ANMs), formal and informal groups, and AYUSH doctors of Mobile Health Teams

Deloitte team conducted face-to-face interviews with government officials at state, district and block-levels and a few community interviews. Given the need for local language speaking investigators and stringent timelines to conduct community in-depth interviews and focus groups, Deloitte also inducted an agency with social research experience and resources to handle qualitative data collection in the study states. To sensitize research agency about the study, Deloitte conducted a training of field managers in Delhi on 10th December, 2015. Further, in each study state, the Deloitte team and agency project manager conducted a one-day classroom training for all field investigators, local supervisors and transcribers. The training session covered research ethics, informed consent, RBSK details, goals and objectives of the study, and interview guides to be administered. It also covered ways to handle possible emotional reactions due to sensitivity of the questions, and tips on interviewing, probing, confidentiality, etc. In addition, mock interviews were conducted both during the classroom session and in community settings to ensure that the investigators were familiar with the interview guides.

### **Process of data collection**

In each district, data collection was managed in the following manner:

- Deloitte coordinated with RBSK Mobile Health Teams during their visit to the states to get the database of children in the age-group 6weeks-6years and 7-18 years who were screened to have any of the 2Ds
- Field managers were responsible for locating the respondents in the appropriate categories using the database, highlighting any shortfalls in the sample, managing timely collection of data, and carrying out focus group discussions

Prior to data collection, Deloitte was apprised by MoHFW that RBSK screening for newborns had not begun. Deloitte was, instead, asked to interview caregivers of newborns who may or may not have 2Ds. Most of these interviews were done at Delivery Points either at the District Hospital or at a CHC/PHC.

During the field visits, it was observed that in a few states, it was difficult to locate children aged 0-18 years with some form of disability or delay but not screened by MHTs. Through discussion with UNICEF, a protocol was developed to compensate for shortfalls in this category. The protocol ensured that at least 5 contact points (AWWs, School Teachers, GP members, ASHAs and local village doctors / RMP) were accessed by the field agency in each of the three villages in each block that have least number of children screened with 2Ds as per the RBSK database. The flowchart with the protocol is appended in Annex 2: Protocol to locate unscreened children.

### **Monitoring quality of data collection**

To ensure that quality of field study was maintained, the Deloitte team led as well as monitored a sample of field interviews in each state. Daily and weekly status updates sent by the field agency were used to monitor progress on the field study and to implement any mid-course corrections. In addition, verification of ~10% physical copies of interview guides was done.

Data collection took place from 15th December 2015 to 31st March 2016, spanning 14 weeks. All community-level in-depth interviews were conducted in local language, in the form of written notes and audio recordings. The setting for data collection ranged from homes and schools, to the facility where the caregivers were available for the interviews.

### **Ethical Considerations**

Participation was voluntary and the informed consent form was read out to the respondents and their verbal consent was sought. The informed consent form was revised to strengthen the confidentiality clause as the study was collecting names of respondents. The revised informal consent form and approval for the study has been submitted to UNICEF in a separate annexure along with study tools. Ethical approval was obtained from Institutional Review Board of Health Media Lab, USA. All results are presented in an aggregated, anonymous manner with the least possible identifying information.

Despite toning down the sensitivity in the caregiver interview guides, a few caregivers may have undergone psychological distress due to the nature of questions and the sensitive topics covered. Wherever possible, the team made the mobile numbers of MHT teams available so that such caregivers could avail benefits of RBSK.

All the photographs used in the report have been taken by Deloitte team after obtaining verbal consent from the respective individuals.

### **Data Analysis**

Qualitative data collected through in-depth interviews and focus groups was collated by converting audio recordings into English transcripts. In addition, notes made by the interviewers were also transcribed and added to enrich the transcripts. Further, a few rounds of data cleaning activities were conducted to streamline the analysis of transcripts. Each of the 878 transcripts was checked for accuracy, consistency, completeness and cohesiveness. All the analysis and coding was done using Microsoft Excel.

Deloitte team read and re-read the transcripts and identified key variables for coding. A codebook was prepared for key variables with definition of the codes. Similar codes were grouped to form themes. Content analysis was also done in the form of counting frequencies. The relevant quantitative data was extracted and synthesized into graphs and charts. Findings have been analysed and presented in the subsequent chapters.

## Limitations of the Study

This study was unique in capturing Knowledge, Attitudes, Beliefs, and Practices of 878 caregivers of children with 2Ds and over 170 community members, and 80 Government Officials across Health, Education, WCD, and Disability. While the study had several strengths in terms of comprehensiveness of knowledge, attitudes, beliefs, and practices of caregivers with children with 2Ds, it also had a few limitations:

- Since newborn screening had not been initiated at the time of the research (December 2015 – March 2016) in the study states, it was not possible to capture knowledge, attitudes, beliefs, and practices of caregivers of newborns screened to have either a birth defect or a developmental delay. However, caregivers of newborns were interviewed to obtain overall perceptions regarding children with 2Ds.
- While the study intended to cover 160 children in the category of unscreened and having a condition (of either a birth defect or a developmental delay), there were field-level challenges in locating such children. This was highlighted to UNICEF during the very first field visit to Aurangabad in Maharashtra. A protocol was then devised to cover the shortfall as elaborated earlier in this section.



# Chapter 3a: Key Findings for Primary Caregivers

## Key Takeaways:

This chapter summarises the key findings from in-depth interviews with 878 caregivers of children who have been screened to have a birth defect or development delay, unscreened children suspected to have a 2D, normal children, and newborns.

## Socio-demographic profile of caregivers

- Study represented diverse segments of rural population in terms of income, education, religion and caste
- Nearly 60% of the respondents interviewed had a children with 2Ds, 33% of them had children with developmental delays, and 22% of them had children with birth defects
- CHD was found to be most common birth defect, whereas language delay was the most common developmental delay

## KABP summary for Caregivers

Aspects	KABP summary
<b>Knowledge</b>	<ul style="list-style-type: none"> <li>• About 55% respondents are aware of RBSK, Of these respondents, 53% had learnt of RBSK through AWWs</li> <li>• Most caregivers are unaware of any technical or medical details of their child's condition; very few were able to explain the condition in medical terms.</li> <li>• About 40% of the caregivers' of children with birth defects are aware of their condition since birth, since developmental delays takes some time to manifest, only 15% of the caregivers of children with developmental delay are aware of their condition since birth</li> </ul>
<b>Attitudes</b>	<ul style="list-style-type: none"> <li>• Over 50% of caregivers' were plagued with feelings of worry or depression when they found out about their child's condition, majority of the caregivers' worry stemmed from thinking about the future of their child, especially when the parents would no longer be around to take care of their children</li> <li>• Although, caregivers were sad, worried or depressed, nearly 30% of the respondents had tried a variety of treatment options including medical care, Ayurveda, and other forms of healing</li> <li>• Nearly 32% of the respondents felt that the community members encouraged them to seek medical care. 24% of the parents/caregivers of children with 2Ds shared that community members were sympathetic towards them</li> <li>• More than 40% of respondents felt that ASHAs and AWWs were only playing a role in provision of information, and often offer verbal solace</li> </ul>
<b>Beliefs</b>	<ul style="list-style-type: none"> <li>• Majority (55%) of the respondents attributed the cause of the condition to behaviours or practices that were in their control like poor health-seeking behaviour during pregnancy and childbirth, nutrition, etc.</li> <li>• 10% attributed their child's condition to God's wish, black magic, past deeds, or other inauspicious events that are outside their control</li> <li>• 25% of respondents met did not know the cause of their child's condition</li> <li>• Despite a variety of beliefs, majority of the caregivers of children with 2Ds interviewed (80%) believed that their child's condition can be cured completely</li> </ul>

Aspects	KABP summary
Practices	<ul style="list-style-type: none"> <li>Parents have a higher preference to go to the private sector for the initial screening and diagnosis. 35% of parents sought treatment at private sector and had incurred an average out-of-pocket expenditure of 45,000 INR. Nearly 16% of parents sought treatment at government health facilities, whereas, only 7% of parents have tried alternative forms of therapy such as traditional healing, Ayurveda, etc.</li> <li>25% of the respondents expressed that mother was the primary decision-maker for choosing treatment for the child. About 30% of them felt that decision-making was jointly done by the parents together</li> </ul>
<b>Barriers and Enablers summary for caregivers</b>	
Aspects	Barriers and Enablers summary
Barriers	<ul style="list-style-type: none"> <li>More than 50% of caregivers identified finance as their major barrier. Financial considerations were a barrier both in routine care of the child at home, and to avail treatment for the child at a health facility</li> <li>21% of the caregivers expressed that transport was a key barrier they faced, in reaching a health facility</li> <li>13% of respondents identified poor understanding of the child's condition, medical causes of impairments, course of treatment/care, and treatment options as a major barrier</li> <li>Psychological distress as a function of constant caregiving for children having 2Ds is another barrier commonly faced by primary caregivers</li> </ul>
Enablers	<ul style="list-style-type: none"> <li>Building awareness of RBSK and the importance of early intervention, and its continuum of care approach</li> <li>Complementary health insurance schemes that cover RBSK conditions that decrease the financial burden on the caregivers</li> <li>Introducing a mechanism wherein transport to health facilities is covered or provided, either through RBSK itself or other health programmes</li> <li>Creating a positive experience with the programme for patients and families</li> </ul>

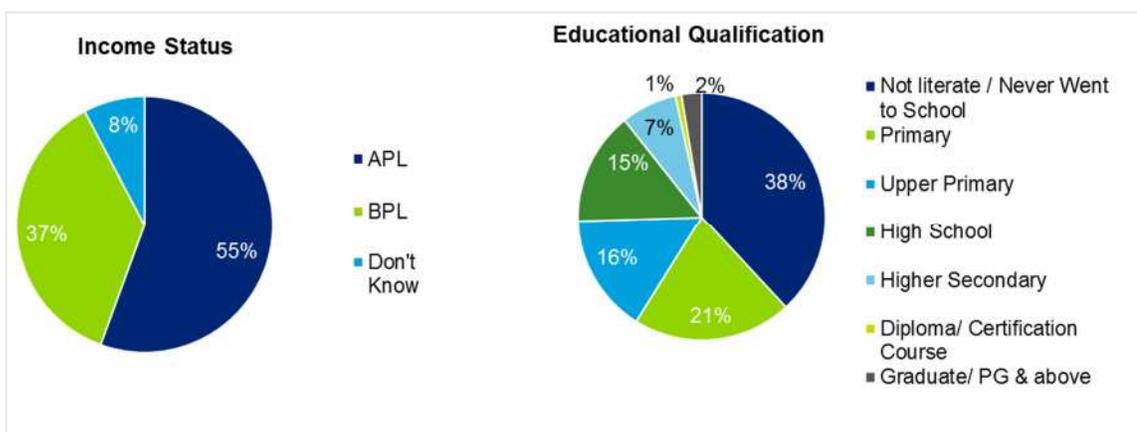
This chapter presents the key findings from analysis of in-depth interviews with 878 caregivers of children who have been screened to have a birth defect or development delay, unscreened children suspected to have a 2D, normal children, and newborns. These findings have been organised into a *KABP* (Knowledge, Attitudes, Beliefs, and Practices) framework. The findings conclude with the key barriers

faced by these caregivers and enablers or facilitating factors that will allow them to overcome these barriers.

### Socio-demographic profile of caregivers

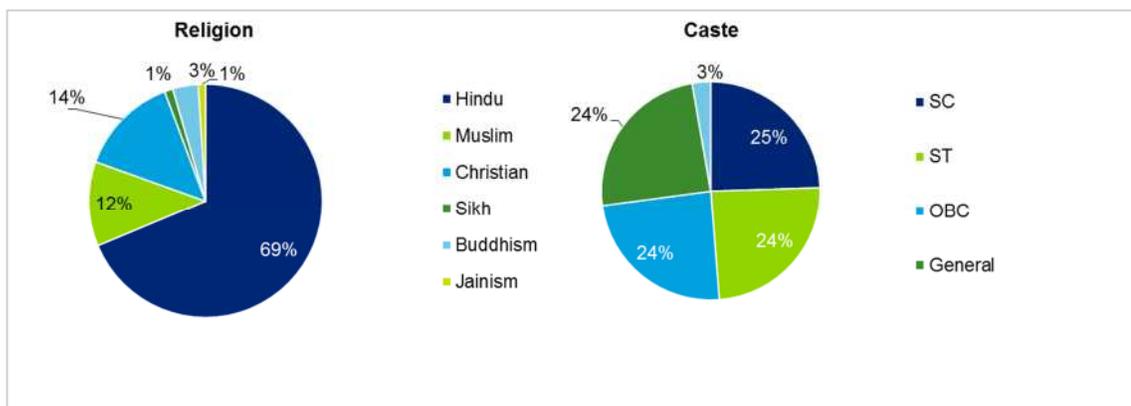
A total of 878 caregivers of children were covered during the study across 8 districts. In terms of caregiver’s income status, 55% of the respondents belonged to APL (Above Poverty Line) category and 37% belonged to Below Poverty Line (BPL). With respect to educational qualifications of caregivers, over one-third (nearly 38%) were non-literate (i.e., never went to school). Mere 22% of the caregivers had either completed high school/higher secondary school and only 2% had a graduation degree.

**Exhibit 8: Percentage distribution of caregivers by income status and educational profile**



With respect to religious backgrounds, 69% of the caregivers interviewed were Hindus, 14% were Christians, 12% were Muslims, and 5% belonged to other religions. All the major vulnerable social groups were equally represented: 25% belonged to Scheduled Castes (SCs), 24% to Scheduled Tribes (STs) and 24% belonged to Other Backward Classes (OBCs).

**Exhibit 9: Percentage distribution of households by religion and caste**



In terms of gender break-up among children with or without 2Ds, 57% of them were males and 43% were females. In addition, the age group of children covered and nature of birth defects and developmental delays covered in the study are depicted below in the Table 6.

Further, in terms of distribution of children to be covered by age and screening status, majority (32%) of the children screened with 2Ds were in the school-going category (6-18 years), followed by 22% in the

Anganwadi category. 4% of the children aged 0-18 years were in the unscreened category; these children have some form of disability, but had not been screened by the RBSK system at the time of the study. It must be noted that since the programme is fairly new (with different stages of implementation in different states) and due to the difficult terrain-specific constraints in Tripura and Meghalaya (making it difficult for MHTs to achieve daily targets), there were limitations on being able to find sufficient number of screened children with 2Ds. However, since this study also involves understanding community knowledge, attitudes, beliefs and perceptions on children with developmental delays and defects (or children with special needs), the shortfall was covered by interviewing caregivers of apparently 'normal children' (without any 2Ds).

Category	Children having a disability (including 2D) Numbers Covered (%)	Apparently 'normal' children Numbers Covered (%)
<b>Newborn (0 – 6 weeks)</b>	11(1 %)	207(24%)
<b>Anganwadi (6 weeks – 6 years)</b>	195(22%)	10(1%)
<b>School going (6 – 18 years)</b>	284(32%)	11(1%)
<b>Unscreened (6 weeks – 18 years)</b>	38(4%)	-
<b>6 weeks – 18 years</b>	-	122(14%)
<b>Total</b>	528(60%)	350(40%)

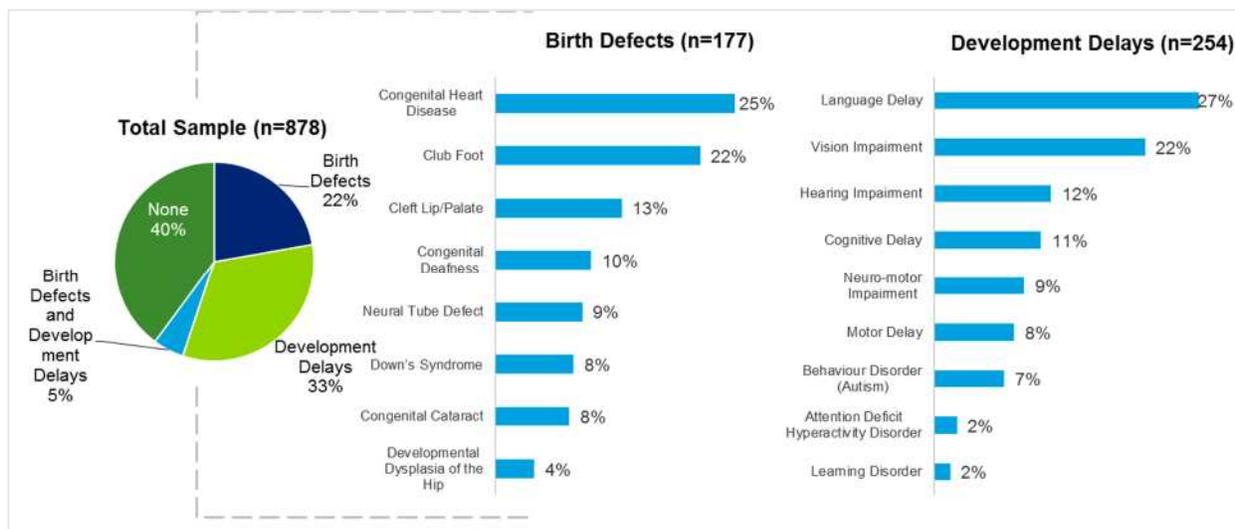
*Table 6: Category of children in different age groups by screening status<sup>22</sup>*

Children covered by type of 2Ds is depicted in the exhibit below. Of the caregivers interviewed, 33% of them had children screened with only developmental delays, 22% of them had children with only birth defects, and 5% of them had children had both developmental delays and birth defects. 40% of them interviewed did not have a child with apparent '2D', i.e., these were either newborns (so they were not screened to have a 2D), or apparently 'normal' children in the age group (0-18 years).<sup>23</sup>

In terms of birth defects, Congenital Heart Diseases (CHDs) were found to be the most common, 25% of the children were screened to have a CHD, followed by club foot (22%). Cleft lip / palate (13%), and congenital deafness (10%) were also found to be the third most common type of defect among children of caregivers interviewed. Whereas, In terms of developmental delays, language delays were most common (27%), followed by vision impairment (22%) and hearing impairment (12%). Some of the infrequently found delays include learning disorder (2%), or attention deficit hyperactivity disorder (2%). This was corroborated by even the MHTs, who noted that it was much more difficult for them to screen for developmental delays, especially learning, and behavioural disorders.

<sup>22</sup> Regular reporting on shortfalls and protocol to cover shortfalls in all categories was regularly discussed with the core client team

<sup>23</sup> As described in the methodology section, in certain districts, there was a shortfall in the number of children screened with a 2D. After following the protocol that ensured at least 5 contact points (AWWs, School Teachers, GP members, ASHAs and local village doctors / RMP) were accessed by the field agency in each of the three villages in each block that have least number of children screened with 2Ds as per the RBSK database and being unsuccessful, caregivers of normal children in the age group 0-18 years were interviewed.

**Exhibit 10: Percentage distribution of children by type of birth defects and developmental delays**

## Community perceptions and norms

### Knowledge

One of the focus areas of the caregivers' study tool was to ascertain the knowledge and understanding of caregivers regarding their child's condition, as well as awareness of government programmes that can support such children. Examining caregivers' knowledge is critical from a communications perspective, in order to target awareness generation activities appropriately.

#### *What do caregivers know of the child's condition?*

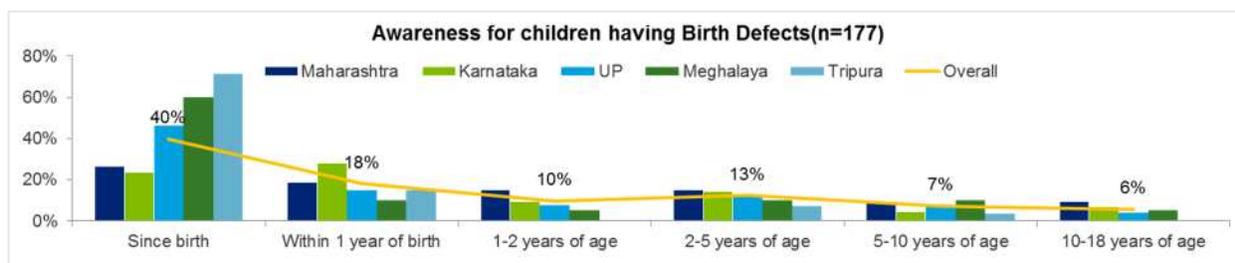
With respect to knowledge, most caregivers are unaware of any technical or medical details of their child's condition; very few were able to explain the condition in medical terms. For visible birth defects or conditions that are easy to understand, caregivers are able to provide a basic physical description of the condition, such as *'the child's legs are not okay and he can't walk properly'* or *'a hole in the heart'*. For other ailments, however, caregivers are only able to describe it in terms like *'brain is not developed'* or *'body is weak'*, without displaying any proper understanding of the condition. This could be owing to the poor educational attainment of 75% of the caregivers (38% of respondents were non-literate, 37% of caregivers had completed only primary level of schooling).

#### *How long have they known of their child's condition?*

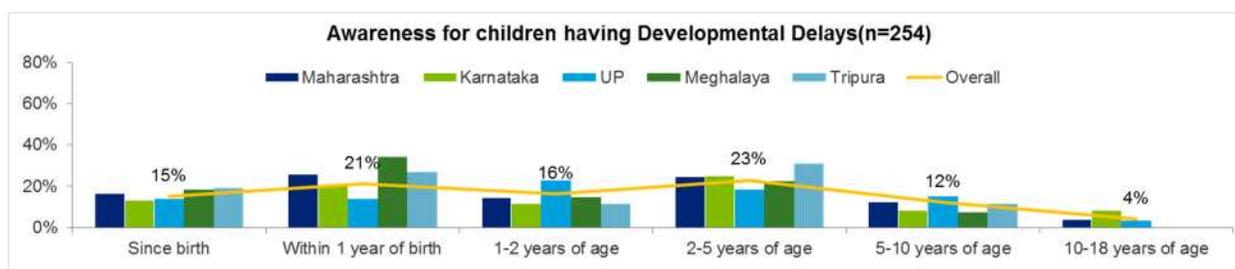
26% of the caregivers whose children were screened to have 2Ds, were aware that their child was 'different' since the birth of their child. This proportion was greater for caregivers of children with birth defects (40%), especially visible birth defects such as club foot and cleft lip that are easily apparent at birth. Whereas for other conditions like developmental delays, which takes time to manifest, this proportion is low at 15%. Caregivers found out about their child's condition much later, only upon consulting a doctor. This distinction between children with birth defects and developmental delays is evident from the exhibits below.

With respect to state-level variation, it was observed that a higher proportion of caregivers in Tripura (71%) and Meghalaya (60%) were aware that their child was 'different' since birth, compared to other study states. However, they also could not articulate condition of the children beyond vague descriptions.

**Exhibit 11: Percentage distribution of caregivers' awareness about the child's condition for children with birth defects**



**Exhibit 12: Percentage distribution of caregivers' awareness about the child's condition for children with developmental delays**

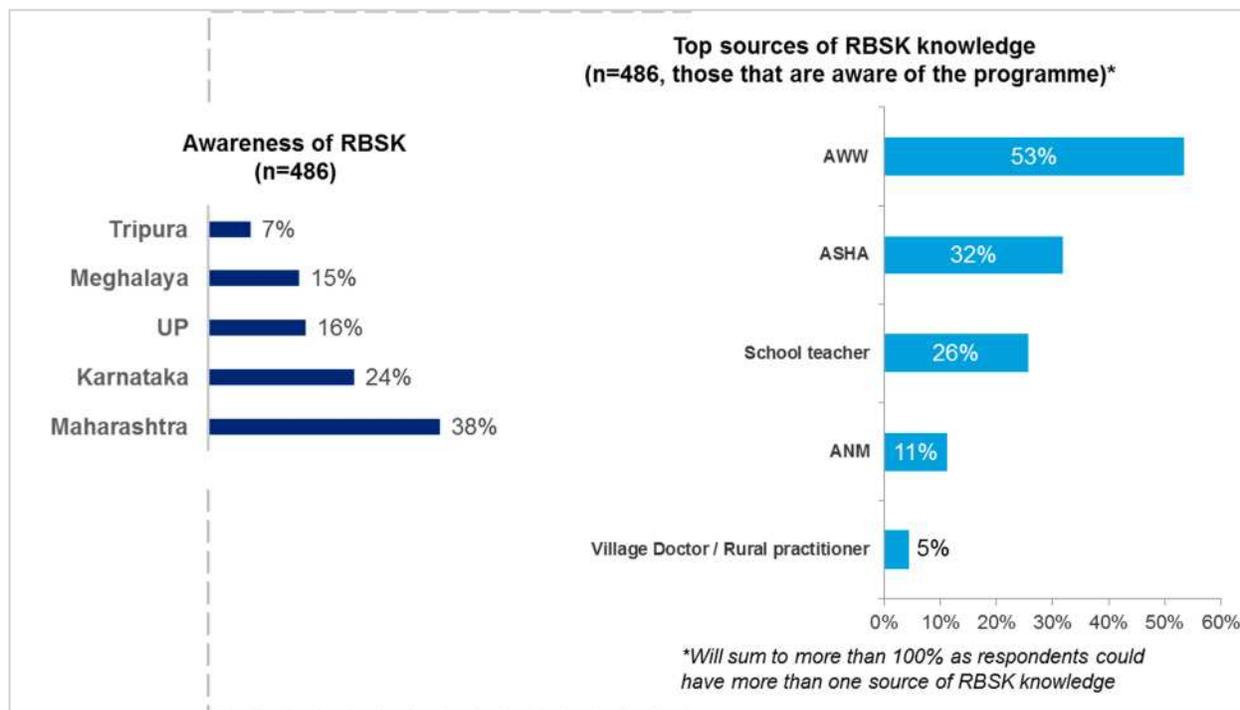


### What do caregivers know of RBSK that aims to minimize disabilities among children?

Almost 55% of respondents were aware of RBSK, measured through their awareness of 'a team of doctors coming to Anganwadi Centres and schools to conduct a head-to-toe check-up for children'. Caregivers in Maharashtra (38%) and Karnataka (24%) had a higher level of awareness of RBSK than other states. This could be possibly attributed to early launch of programmes in these states as well as better performance of outreach activities in these states compared to other study states. The source of information on RBSK were frontline workers including AWWs (55%) and ASHAs (32%) as well as school teachers.

While screening component (i.e., check-ups at schools or AWCs) of the programme is popular among caregivers, a very small proportion of respondents knew of the free treatment component of the programme. Further probing also indicated that a majority of the caregivers were not clear about what the check-up (or screening) meant, and did not understand the potential benefits of screening. They also displayed no knowledge about continuum of care under RBSK. Even the frontline workers and traditional healers interviewed by the Deloitte team were not fully aware of RBSK, and its potential benefits in the form of screening and early intervention and its continuum of care.

The exhibit below depicts the main sources of information on creating awareness of RBSK:

**Exhibit 13: Awareness and source of information on RBSK**

### Attitudes

Parental attitudes towards children with 2Ds was measured using a number of key questions. Since there was no set scale to measure attitudes towards children with a wide variety of delays and birth defects, the Deloitte team came up with a vignette to glean information about their attitudes. The vignette was a story of a caregiver named, 'Kamla', whose daughter 'Radha' had speech and hearing impairment. A snapshot of the vignette is given below in the Exhibit. Respondents were then asked to comment on how the character in the story would feel or act in a given situation. As the focus is on a third person, vignettes are beneficial in research on sensitive topics where the participant may not feel comfortable discussing their personal situation and may conceal the truth about their own actions or beliefs. It is particularly useful in this context because our sample covered caregivers of children with 2Ds, and caregivers of children without 2Ds (i.e., newborns). So, the vignette allowed the respondents relate to the situation and then respond to the statements.

The vignette was followed by a set of statements to explore attitudes of community members including health workers, and teachers towards children with 2Ds. Where appropriate, an attempt was made to encourage respondents to reveal their personal experiences when they felt comfortable to do so. The attitudes revealed by the vignette was then used to ascertain the attitudes of the communities towards children with special needs (CWSN) or children with disabilities.

### Exhibit 14: Vignette on a hypothetical caregiver

*"In a village similar to yours, there is a woman named 'Kamla' who was about 33 years old. She lives with her husband and 4 children. Of her four children, one of them, Radha, was screened to have a hearing impairment. Her daughter has both issues with speech and hearing. Now, imagine 'Kamla' as a woman in your community and please answer the following statements: Please tell us whether you agree with statement or disagree with statement. [1] = Agree; [2] = Disagree"*

Using the aforementioned vignette, attitudes of the community towards children with special needs were ascertained. The table below summarizes key findings.

**Table 7: Response of caregivers on the vignette<sup>24</sup>**

Statements	Agree	Disagree
Families with CWSN are socially excluded	98 (11%)	767 (87%)
CWSN are mocked at by other children	603 (69%)	239 (27%)
CWSN are given less importance by school teachers	383 (44%)	456 (52%)
Mothers-in-law blame daughters-in-law for bearing a CWSN	489 (56%)	327 (37%)
ASHAs support parents of CWSN	663 (76%)	183 (21%)
Having a male CWSN is better/ easier than a female CWSN	543 (62%)	285 (32%)
Parental aspirations for CWSN are same as those for other, normal children	631 (72%)	216 (25%)
Parents of CWSN will use a programme like RBSK if they are aware of it	839 (96%)	11(1%)

#### Outlook towards children with 2Ds

It was observed that, 87% respondents did not feel that the community members in the village would socially exclude caregivers like 'Kamla'. However, 69% of the respondents felt that children with special needs could be mocked at by other children. Upon further probing, respondents also added that since children were playful, and did not possess adequate maturity to understand, they were likely to mock. They also were quick to add that these taunts were completely harmless and no intentional maltreatment was meant towards such children. In fact, even the head teachers corroborated this statement and added that they guide children to treat everybody in the same manner, regardless of their disability.

#### Perceptions regarding mothers-in-law

With respect to the statement on taunts by mothers-in-law, 56% of the respondents felt that the mothers-in-law could blame their daughters-in-law for bearing a child with special needs (or disability). However, they also added that this would only happen in a fit of a rage if the mothers-in-law tended to be angry with their daughters-in-law. The in-depth interviews with mothers-in-law revealed that most of them are supportive and partake in caring for the child with special needs. It must be noted from Deloitte's field visits to the rural areas that, the family dynamics is changing even in the rural context – most families tend to be nuclear, with in-laws living away or in another village. In such situations, the mothers-in-law are not around to support the parents in taking care of such children.

<sup>24</sup> Doesn't add up to 100% as some respondents chose not to respond and were marked as (No Response)

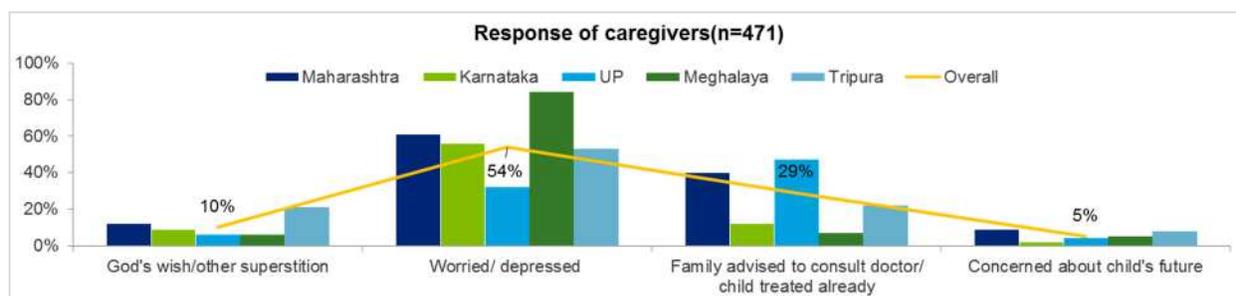
### Perceptions of girl children with special needs

Given the gender disparities in India witnessed by high female foeticide rates, low sex ratios, and poor status of women, the research team including the client counterpart felt that it was prudent to explore gender differences using the same vignette. 62% of the respondents felt that it would be easier for caregivers like Kamla to raise a male child with special needs than to raise a female child with special needs. While gender continues to colour even the perception of children with special needs, most respondents qualified this statement by adding that their main worry was regarding the long-term safety and security of female children with disabilities. They echoed social norms in India around daughters being a *'paraya dhan'*, and the fact they had to eventually be married off, and live with their husband's family. The caregivers also worried that the disability status of girl children could even impede their chances of getting married or that the parents would have to struggle to find an appropriate match for such girls.

Attitudes also included response (i.e., sentiments) of parents when they realized their child had a condition, response of the community members and the frontline health workers towards the families having children with 2Ds.

### Caregivers' response when they learned about their child's health condition

**Exhibit 15: Response of caregivers upon knowing the condition of their child having 2Ds**



Every parent dreams about his/her child being 'perfect', and when a child is detected to have a defect/delay/disability, it is likely to bring about feelings of anxiety, guilt, emotional instability, self-pity and/or hopelessness.<sup>25</sup> This study concurred with the findings from research conducted earlier, over 50% of the caregivers of children with 2Ds were plagued with feelings of worry or depression when they found out about their child's condition. Majority of the caregivers' worry stemmed from thinking about the future of their child, especially when they would no longer be around to take care of their children. As noted earlier in the vignette on Kamla, the caregivers' anxiety for female children with special needs was much higher.

*"We're worried about daughter's marriage, daughters are 'paraya dhan'<sup>26</sup> (someone else's wealth)"*

- Grandmother of a 7-year old girl child with squint and speech delay, Etah, UP

Although, caregivers were sad, worried or depressed, 80% of them felt that their children could be cured and many of them took a stance to *'do something'* about it rather than continue to be helpless about their child. Nearly 30% of the respondents had tried a variety of treatment options including medical care,

<sup>25</sup> Chandramuki, et al., Attitudes of Parents towards Children with Specific Learning Disabilities – Disability, CBR and Inclusive Development (DCID), 2012

<sup>26</sup> In India it is said that a girl child is a 'PARAYA DHAN' meaning she is someone else's wealth which her parents have to keep till her rightful owners claim her (i.e., her husband's family)

Ayurveda, and other forms of healing. The tendency to go for medical treatment was higher in caregivers in UP (47%) and Maharashtra (40%).

*“We became very sad when we came to know about her situation.... We wondered that how she will get well.... Mother-in-law advised to go to some good doctor or hospital...”*

- Mother of a 9-year old child with hearing impairment, Jalna, Maharashtra

*“...What do we feel...we just hope that he becomes better soon...?”*

- Mother of a female child with multiple delays, Raichur, Karnataka

### **Fatalistic attitude**

There were about 10% of caregivers who had a fatalistic attitude, attributing the ‘disability’ as God’s will and did not show much motivation to overcome the disabilities. These attitudes tended to be more common in Tripura (21%). These caregivers also expressed that they wanted their children to get better, however, did not take up any concrete measures to improve the health condition of their children.

*“We feel very bad but we have left it to divine intervention”*

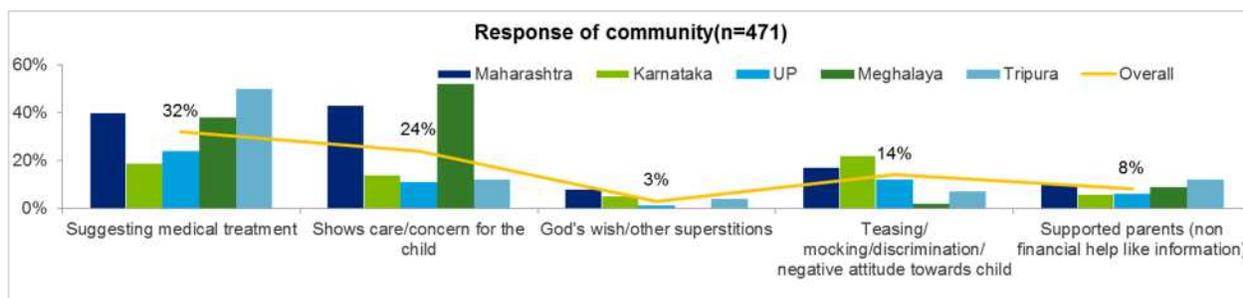
- Father of a 4-year old child with neuro-motor impairment, Dhalai, Tripura

*What can I do when Allah has made her like this.. behri and gungi (deaf and dumb)?*

- Mother of a 10-year old child with hearing impairment, Barabanki, UP

### **Caregivers’ response on community members attitude towards their children having 2Ds (including family members, neighbors)**

**Exhibit 16: Response of community members upon knowing the condition of the child**



Nearly 32% of the respondents felt that the community members encouraged them to seek medical care, with an additional 8% of community members even offering support in the form of useful health information such as contact details of a doctor / surgeon, etc. Further, nearly 24% of the parents/caregivers of children with 2Ds shared that community members were sympathetic towards them, this proportion was much higher in states like Meghalaya (52%) and Maharashtra (43%) compared to other study states. However, the respondents also indicated that hardly anyone had offered any tangible financial support or physical support such as caretaking of other children in the family, etc. Meghalaya was the only exception where the community members are offering support in the form of taking care of daily routine activities in the absence of primary caregivers’. However, this was found only in tribal communities where the sense of community ownership still exists.

*“Community members are supportive... They provide information for her treatment... they use to talk to us about her problem”*

- Grandmother of a 4-year grandchild with clubfoot, Jalna, Maharashtra

Interviews with caregivers who had children with 2Ds also revealed that a few (3%) community members were feeding into the fatalistic attitudes. Further, 14% of the respondents shared that some community members even taunted and stigmatized them for bearing children with special needs, this proportion was much lower in states like Meghalaya(2%) and Tripura(7%) compared to other study states. It could probably be attributed to more inclusive approach followed in tribal culture.

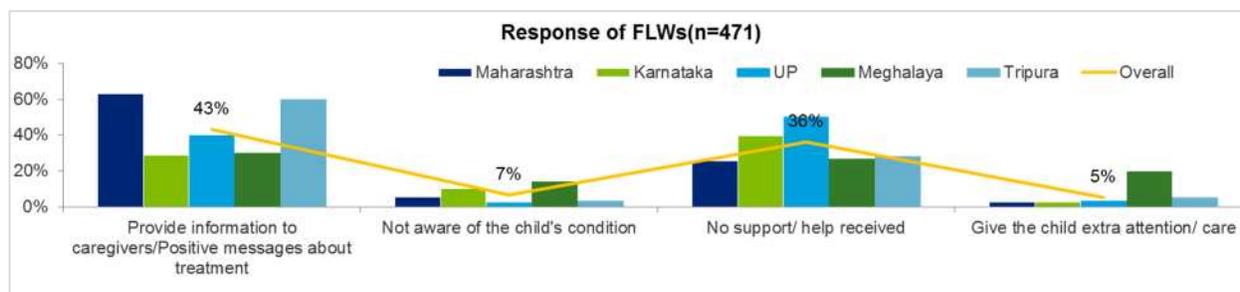
*“...they used to taunt us sometimes... Some people say it is destiny.... They say, God knows why this has happened with your daughter... you never did wrong to anyone...”*

- Father of a 7-year old child with visual impairment, Ambad, Jalna

Overall, the study also revealed that most parents lacked opportunities to share their experiences and gain support from friends and extended family members. Presence of such platforms and support groups could help families in gaining confidence, improving self-esteem and boosting their determination to bring up their children with special needs.

### **Caregivers' response on frontline workers (ASHAs, Anganwadi Workers, and ANM) attitude towards their children having 2Ds**

**Exhibit 17: Response of FLWs upon knowing the condition of the child**



About 43% of respondents felt that ASHAs and AWWs were only playing a role in provision of information, and offering verbal solace. However, over 33% of the respondents having children with 2Ds reported that ASHAs and AWWs do not play any role or support them in any way possible. This could be because in most study states, interactions with frontline workers revealed that health workers themselves had a very low understanding and knowledge of RBSK, and its details. Since they do not know enough, they are merely steering families towards the public health care system.

*“The ASHA of our village did not help me, she even did not tell me about anything during my pregnancy, I wish she had told me about antenatal check-ups. They take salary from government but don't do anything for the community....”*

- Mother of a female child with cleft lip, Kalaburagi, Karnataka

ASHAs are playing a limited role in implementation of RBSK since they do not receive any incentives for the programme. AWWs mobilize parents to come to the Anganwadi centres along with their children when the MHT comes for screening.

*“Whenever any doctor come to visit our village, Anganwadi staff used to call us every time”*

- Father of a male child with language delay, Jalna, Maharashtra

## Beliefs

Interviews with caregivers also focused on ascertaining caregivers’ beliefs surrounding their child’s condition, in terms of both its cause and treatment. It is important to know whether caregivers understand the root cause of the health condition, or if they attribute it to external factors outside their control. It is also imperative to understand caregivers’ beliefs regarding whether the condition can be cured, as that impacts health seeking behaviour.

*A small subset of respondents feel that the child’s condition is due to God’s wish or other such causes. A larger number, however, felt it was due to factors in their control such as poor habits during pregnancy.*

10% of caregivers attributed their child’s condition to God’s wish, black magic, past deeds, or other inauspicious events that are outside their control. Such respondents tended to have correspondingly fatalistic attitudes towards treatment of the child’s condition, as they felt that too was outside their control or not possible, as the condition was not curable. Such respondents also had a greater preference for going to a traditional healer as compared to the formal health system.

*“...because I cut vegetables during solar eclipse....”*

- Mother of a female child with cleft lip, Etah UP

55% of caregivers attributed the cause of the condition to behaviours or practices that were in their control, such as poor health-seeking behaviour during pregnancy such as missing antenatal check-ups, not consulting or following the advice of doctors, premature or late delivery, or unhygienic practices in the health facility during delivery.

*“...If the mother is not immunized during her pregnancy, then a child can develop a disability...”*

- Mother of a regular child, West Khasi Hills, Meghalaya

A small proportion (5%) of respondents also stated that it was due to consanguineous marriages, while a few named genetics and hereditary problems.

*“..We had inter relation-marriage that is why we had a child with this problem...”*

- Mother of a 7-year old girl child having Down Syndrome, Kalaburagi, Karnataka

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*Consanguineous marriages resulting in 2Ds among children were especially common in Karnataka, where respondents also seemed to understand it as the reason behind the condition. Consanguineous marriages are common and culturally and socially favoured in South India; they are estimated to constitute 20–50% of all marriages in North Africa, West Asia and South India<sup>27</sup>*

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<sup>27</sup> Hamamy H. Consanguineous marriages: Preconception consultation in primary health care settings. Journal of Community Genetics. 2012

### **A large proportion of respondents are unaware of the cause of the condition**

Nearly 25% of respondents met did not know the cause of their child's condition. As a result, a lot of caregivers also did not know how such a condition could have been prevented or can be prevented in the future.

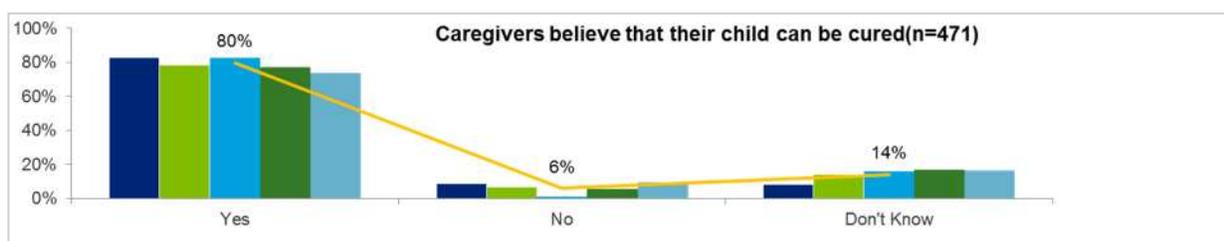
*"His brain has water -that's why he's weak - it will improve and no treatment is required"*

- Father of a male child with neuro-motor impairment, Jalna, Maharashtra

Regardless of caregivers' beliefs regarding the child's condition, many of the caregivers expressed a desire to have their child get better, and stated that they would do anything to have that happen. Several caregivers also said that if they had known about the child's condition sooner, they would have taken the appropriate steps earlier, highlighting their willingness for early intervention.

### **Most caregivers feel that their child's condition can be cured**

**Exhibit 18: Believe of caregivers on the curability of their child having 2Ds**



Majority of the caregivers of children with 2Ds interviewed (80%) believed that their child's condition can be cured completely, while a few (14%) did not know whether their child would be cured completely. Only 6% of respondents believe their child cannot be cured; this is reflective of the optimistic outlook of parents towards their children with 2Ds, and is also an indicator of positive health-seeking behaviour and willingness to avail treatment for their children. However, once the parents of children with 2Ds encounter obstacles within RBSK or the government health system, their perceptions regarding treatment or cure for their child tend to become somewhat negative. They also experience how money can become a real stumbling block to receiving medical treatment, and start becoming cynical and pessimistic.

*"...If the system cannot do anything, then why bring it up and diagnose it..."*

- Father of a female child with Neural Tube Defect, Raichur, Karnataka

## **Practices**

### **Steps taken by caregivers to improve their child's health status?**

Practices were measured by understanding the caregivers' preferences for treatment including private, government, and informal health systems, and alternative forms of treatment and the reasons for those preferences. Since health-seeking practices differed by type of condition, severity of the condition, age of the child with a condition, and personal experiences of caregivers, an attempt has been made to categorize them into different types:

#### **TYPE 1: ALREADY EVALUATED PRIOR TO THE LAUNCH OF RBSK**

Significant proportion of respondents had older children (aged 10-18 years) with 2Ds, were already aware of their child's condition and had made several attempts to seek medical care. RBSK was launched only 3

years back, and these parents had already proactively engaged with the private medical system earlier. These parents chose to go to the private sector as their first-point-of-care since they did not feel that the government system had the capacity to deliver. They felt that the private sector offered them a quicker, effective, and adequate quality of care. A significant proportion of parents had continued medical care through the private sector, at times, even taking loans to ensure the treatment could be continued. However, for a few delays such as behaviour disorders or neuro-motor impairment when the child did not respond to treatment, they stopped seeking further medical care. Having spent sufficient time and money on treatment and having saturated options of care known to them, they have 'accepted' their child's condition and continue manage such children at home.

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*Many parents chose private sector as their first-point-of-care because they do feel that the government health system does not have the capacity to deliver. Moreover, they lose a lot of time in waiting at the centre, making repetitive trips, spending on diagnostics, and end up not getting the expected 'quality of care'.*

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## **TYPE 2: SCREENED BY RBSK TEAM, WENT TO THE FIRST REFERRAL CENTRE AND DID NOT GET APPROPRIATE 'CURE' FOR THEIR CHILDREN**

There were a group of parents whose children were screened to have either a birth defect or a developmental delay by the MHTs. Parents were apprised of the condition of the child only after screening carried out by MHTs. This was typical of cases such as congenital anomalies and/or milder forms of developmental delays including behavioural disorders that are not evident. Often parents do not have knowledge of signs and symptoms of these conditions or knowledge of delayed milestones. These children suspected to have any of the 2Ds are referred to a higher health centre.

Most parents whose children were screened with a 2D took their children to the nearest point-of-referral – DH/CHC/PHC, depending upon the case. In schools, unlike in Anganwadi centres, parents are informed through teachers about their child's condition. The teachers also handover Child Health Screening Card or a letter which states the child's condition. Since the MHTs approach parents in the community, their 'expectations' in terms of getting some form of 'medical care' from the health system are heightened. However, upon reaching the health centre, they do not receive the necessary care and treatment, often reinforcing the 'mistrust' in the public health system. In many cases, parents ended up waiting for extended periods of time, had to undertake repeat visits and still did not receive the 'benefits of free treatment and care', as envisioned in the program. During such episodes, they usually tend to give up on the government health system and try treatment from the private sector.

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*There are sizable number of parents who have understood the child's condition and say that if nothing can be done about it, why give us hope. These parents have obtained an understanding that the child has a developmental delay or a birth defect.*

*Quite a few parents of children with developmental delays who were informed of a long-term rehabilitative approach were unable to take up repeated, follow-up services. Time, money, distance to the facility, and lack of options to take care of other children while they away, are some of the major barriers to seek care for such parents.*

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An important point that emerged during the study is that parents are not clear about the **cure vis-à-vis care** approach – this tended to be a major impediment for parents to access follow-up services and care. Parents perceive all conditions to be ‘curative’, however, RBSK covers a variety of developmental delays including Down Syndrome, congenital deafness, speech delay, neuro-motor impairment, language delays, that cannot be fixed through medicines immediately. These conditions require protracted treatment, mostly, rehabilitative care. However, parents do not have an understanding of either the condition or the prolonged time it requires, often giving up after a few trips to the centre expecting a ‘quicker cure’. Even the public health system does not sufficiently counsel parents on the rehabilitative, long-drawn-out care approach required to deal with developmental delays.

*“... They say that child has kum dimaag (less brain)...he needs some exercise for more than 3 years... we are financially weak. We cannot afford going to the hospital again and again...we hope he can be independent for basic routine activities (like bathing, eating)”*

- Mother of a 5-year old child having Down Syndrome, Dhalai, Tripura

### **TYPE 3: SCREENED BY RBSK TEAM AND GOT TREATMENT**

A few parents of children with birth defects such as congenital heart diseases, club foot, and cleft lip/palate received treatment in the form of surgeries. Most of these surgeries were accomplished through Memorandum of Understanding(s) with private health providers and/or support from non-profits such as Cure International, Operation Smile, etc. In Maharashtra, the MHTs were proactive and encouraged parents to seek care in cities such as Mumbai, Pune, etc. It also helped that Maharashtra has presence of many philanthropic institutions such as Shirdi Trust that offer surgeries at ‘almost nil cost’ to poor families. For instance, Shirdi Trust conducts free surgeries for children with congenital heart diseases including free diagnostics and medicines. Further, parents are provided free stay and food along with their children during the treatment or surgery. However, distance to Mumbai/Pune and long waiting periods for surgeries at these institutions were noted as disadvantages.

*"We were very sad after knowing that my daughter is having this problem, since we are daily wage labourers we cannot afford the treatment, but my child is okay now, we got the treatment done under Rajiv Gandhi Arogyashree through RBSK"*

- Mother of an 11-year old child operated for CHD, Aurangabad, Maharashtra

In addition, it was observed that presence of functional DEICs were a huge enabler. For instance, in Jalna, the children screened to have 2Ds were evaluated by a paediatrician at the DEIC. In such cases, DEICs were found to be catering to the need of the programme, by being a ‘one-stop-centre’ for availing evaluation as well as repetitive rehabilitative care and therapy, as the case may be. This was observed even in Meghalaya where the DEIC at Shillong was getting referrals from SNCUs (Special Neo-natal Care Units) and from children screened across the district and even nearby districts.

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*Some parents of children with birth defects made several attempts to avail surgical procedures for their children, but had given up when they could not arrange sufficient funds for the surgery. However, in states such as Maharashtra, Karnataka, with enabling and complementary state-specific health insurance programmes such as Rajiv Gandhi Jeevodayee Arogya Yojana, Vajpayee Arogyashree, families were able to make use of them for RBSK conditions as well*

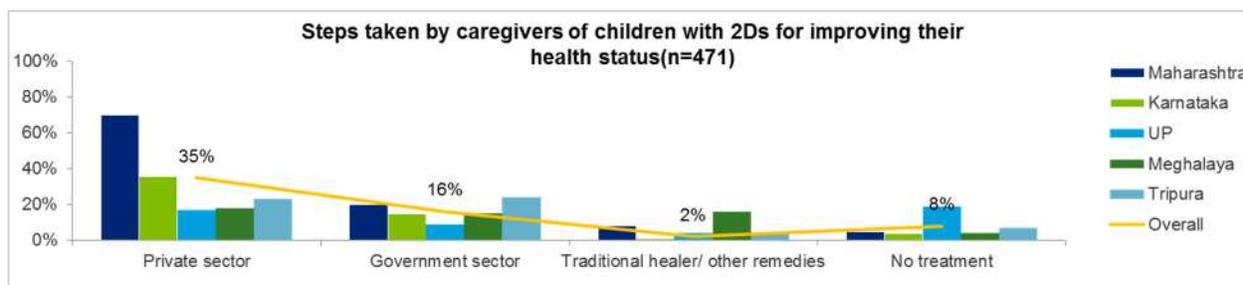
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**TYPE 4: SCREENED BY RBSK TEAM AND DID NOT GO TO FIRST REFERRAL CENTRE**

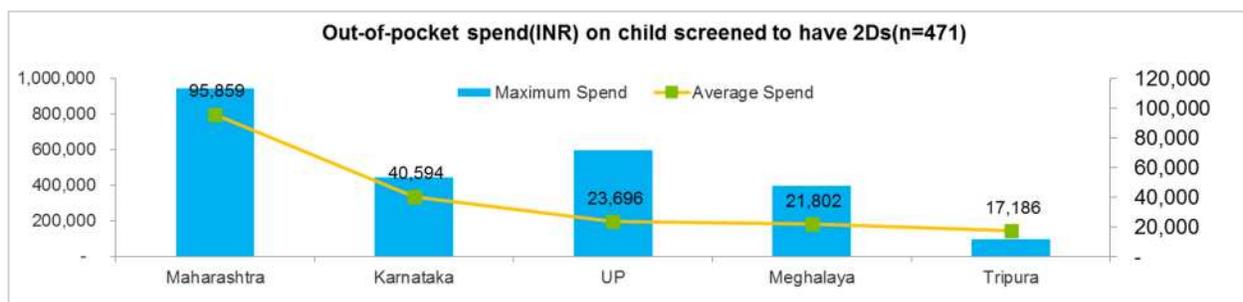
In this case, the parents are informed about the condition of the child either through MHTs or via teachers at schools. However, due to a variety of factors including financial barriers, poor support from home, having the responsibility of other children at home, and distance to the facility, they are unable to continue the treatment required. Some other families also did not feel the necessity to seek care or treatment. This was true of families in tribal areas of Meghalaya and Tripura where communities also have less faith on service providers. They also tend to have a fatalistic attitude, and have less motivation to seek formal healthcare.

**Typical Practices of Parents**

**Exhibit 19: Practices followed by caregivers for treatment of their child having 2Ds**



**Exhibit 20: Out of pocket expenses incurred by caregivers for treatment of their child having 2Ds**



It was observed that, **most caregivers have a higher preference to go to the private sector** for the initial screening and diagnosis. 35% of caregivers sought treatment at private sector and had incurred an average out-of-pocket expenditure of 45,000 INR. This proportion was much higher in Maharashtra, where 70% of the respondents sought treatment at private health facilities and incurred an average out-of-pocket expense of over 90,000 INR, attributable to presence of a larger private health network in Maharashtra compared to other study states.

Further, nearly 16% of parents sought treatment at government health facilities, this proportion was higher in Tripura (24%) compared to other study states. This could be attributed to high dependency of caregivers on government health system in Tripura due to absence of the private sector. In addition, 7% of parents have tried alternative forms of therapy such as traditional healing, Ayurveda, etc.

**Curative worldview of medicine**

Parents have been pro-active and have attempted to seek medical care for their children with 2Ds. Parents largely view modern medicine as highly effective, almost to the extent of being a ‘magic bullet’ for their child’s health conditions. Parents who see medicine as ‘curative’ however, tend to get frustrated with

the 'system' when the cure is not available. This category of parents are inclined to sell their belongings and generate money for treatment of children with defects (that typically has a quicker fix such as surgeries). However, for children with developmental delays who require protracted treatment with minimal incremental results after each visit to the facility, poorer parents are less inclined to take forward such treatment options, as it involves repeated visits, opportunity costs, travel time, and money.

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*There were state variations in terms of practices of parents of children with birth defects and developmental delays – most parents in Maharashtra trust 'medical care' and saw the effects of modern medicine as useful for their children. Similarly, in UP, it was observed that parents took their children with 2Ds to a private health provider due to non-availability of specialists in the government health system or low confidence in the government set-up. However, in the north-eastern states of Tripura and Meghalaya, the attitude of the communities tended to be fatalistic and they had less faith in 'modern medicine', they felt that the child's condition was God-given, and it was 'meant-to-be'. In addition, the tribal communities did not accept or relate to the Mobile Health Teams as they belonged to a different tribe. They continued seeking treatment either through churches (in Meghalaya) or with local medicines dispensed by community-based traditional healers on whom they had a lot of faith.*

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### Health-seeking behaviour

One of the focus areas of the caregivers study tool was to determine the health-seeking behaviours of caregivers of children with 2Ds (or CWSN) and decision-making around child's health. These behaviours are crucial from a communications perspective, in order to target the right audience for behaviour change actions appropriately.

#### **Where do you take your child with special needs for first level of health check-up and who decides where to take the child for treatment?**

Nearly 53% of the respondents reported visiting their local village doctor<sup>28</sup> or MBBS doctor (private clinic), when their children (with 2Ds) falls ill. However, 32% of the respondents also reported visiting a local PHC/CHC to obtain first level of health check-up and care.

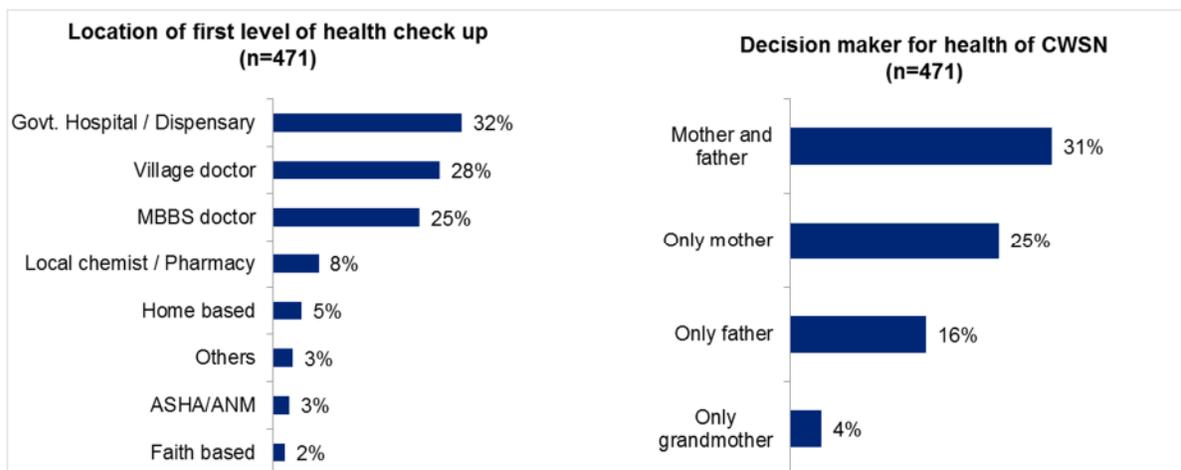
Further, 25% of the respondents reported mothers to be primary decision-maker for choosing treatment option for the child. About 30% of them felt that decision-making was jointly done by the parents together. Upon probing, the team also gathered that the fathers are important in deciding care, especially when surgeries are required, or if the treatment options are expensive and a price factor is involved.

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<sup>28</sup> Village doctors are Registered Medical Practitioners

<sup>23</sup> Sum for location of first level health checkup is more than 100% as respondents have chosen multiple options

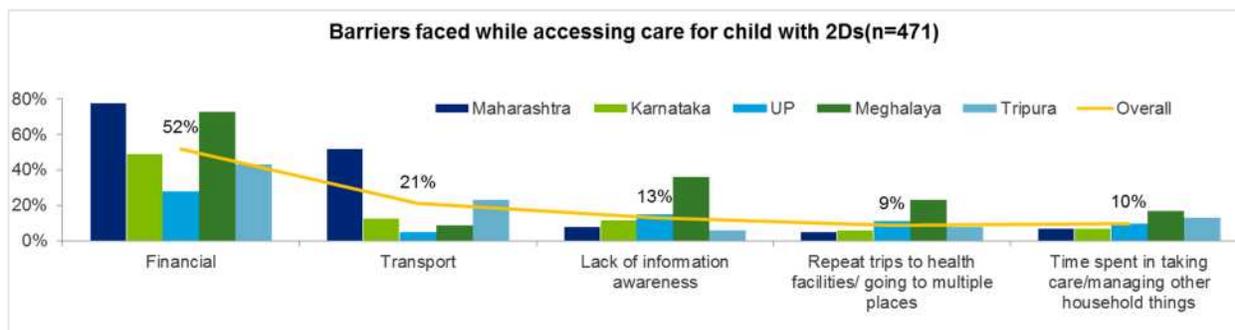
**Exhibit 21: Health Seeking Behaviour<sup>23</sup>**



**Barriers**

The study also focused on understanding the barriers that were faced by caregivers of children with 2Ds, both in terms of challenges/ adjustments faced in day-to-day interactions with their children, and in accessing health care. It is imperative to understand the barriers these caregivers face, in order to tailor a communication framework that adequately addresses these barriers. A detailed barrier analysis using the socio-ecological framework and continuum of care of RBSK is provided in the report on Communication Framework.

**Exhibit 22: Typical barriers faced by caregivers while accessing care of child having 2Ds**



**Financial barriers**

Majority of the caregivers (more than 50%) identified finance as their major barrier. Financial considerations were a barrier both in routine care of the child at home, and to avail treatment for the child at a health facility. Financial barriers mainly occurred in the form of treatment-related costs, including cost of medicines and treatment cost at health facilities, especially private facilities. Most caregivers stated that they would do anything for their child if they were able to afford treatment and did not have financial constraints, and several identified finance as their only barrier.

*“Money is a major issue for us, and because of that, we are unable to do anything for her”*

- Mother of a female child with Congenital Heart Disease, Aurangabad, Maharashtra

It was found during the study that, caregivers had incurred an average of INR 45,000 of out-of-pocket expenses in caring for their child with 2Ds, with some caregivers spending as much as INR 950,000.

Wage loss was also mentioned as a form of financial barrier, in terms of wage loss associated with caring for the child or taking the child to a health facility for treatment. This was especially burdensome for caregivers of children with conditions that require long term care and treatment, multiple trips to health facilities, or lengthy hospital stay. Caregivers often had to skip work or rush home early to care for the child or take him/ her to a health facility, which was particularly challenging for daily wage labourers. In some cases, women were unable to work at all, as the time investment in caring for the child would not allow it.

While staying at health facilities to avail treatment for the child, indirect costs of arranging accommodation, food, and other amenities also served as a barrier for caregivers. Taking care of children back home, while the primary caregivers (typically, mothers) were at the health facility for treatment of the child with special needs was also highlighted as one of the barriers.

*“...there are 5-6 children in the home to take care of, if I take her to hospital, then who will take care of other children, I don't receive any help from my in-laws”*

- Mother of a 7 year old female child having squint, Barabanki, UP

### **Transportation-related barriers**

Another barrier commonly faced by caregivers, especially with respect to accessing treatment at health facilities, was transport-related. 21%<sup>29</sup> of the caregivers expressed that transport was a key barrier they faced, in reaching a health facility. Transport barriers were mainly financial in nature, as most caregivers stated that they were unable to afford transport to the health facility. However, since this was a major barrier expressed by caregivers, it must be discussed independently of other financial barriers. Past studies done on people with disabilities also corroborate our findings and highlight high transport costs as a significant barrier to mobility.<sup>30</sup> A World Bank study conducted in 2007, indicates transportation as one of the top three reasons discouraging people with disabilities from using health services.<sup>31</sup> In addition to the financial implications of transport to health facilities, caregivers also faced barriers relating to accessing health facilities that are at a distance from their village, due to the remoteness of the village. This had implications on both time taken and logistics involved. Such transport barriers were also more common when caregivers had to access health facilities in a different district or state.

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*Transport barriers were exacerbated in hilly and remote regions of Meghalaya and Tripura, where health facilities were located at a much greater distance from villages and were more inaccessible, and harder to reach, due to the terrain*

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<sup>29</sup> This has been reported for only children screened to have 2Ds (n= 471) and were facing barriers for accessing further follow-up and treatment

<sup>24</sup>This has been reported for only children screened to have 2Ds (n= 471) and were facing barriers for accessing further follow-up and treatment

<sup>25</sup>Varghese et al. (2015). Barriers in healthcare access faced by children with intellectual disabilities living in Uttar Pradesh, Journal of Social Inclusion

Further, a few caregivers (9%), especially those with children with developmental delays requiring protracted care, found that they had to make repeat trips to health facilities for treatment, or were sent from one facility to another. This was often without any discernible impact on their child's health, and resulted in a lack of motivation to continue to do so, especially in light of the other barriers they faced while accessing treatment at a health facility.

### **Cognitive barriers among caregivers**

Poor understanding regarding the child's condition, medical causes of impairments, steps that can and should be taken to resolve it, and information on treatment options also served as a major barrier for many caregivers (13%). Predictably, this was more of a barrier for non-literate or uneducated caregivers. Often, this lack of awareness was aggravated by a lack of awareness among the larger community as well, as family and community members often told these families that nothing could or should be done, and thus discouraged them from availing treatment. Lack of awareness or education about birth defects, and developmental delays and concept of early intervention, often kept caregivers from taking the first step towards accessing healthcare, accessing it early enough to make a difference to the child's life. At times, cognitive barriers impede parents' ability to even decide the 'appropriate' future course of action for their child with developmental delays or birth defects, exemplifying the need for adequate counselling and education.

*"His brain has water -that's why he's weak - it will improve and no treatment is required"*

- Father of a 8-year old male child with neuro-motor impairment, Aurangabad, Maharashtra

Among caregivers who chose to avail treatment for their children, poor understanding of the condition and treatment posed as a barrier here too – in terms of an unwillingness or anxiety associated with availing treatment such as surgeries, due to a lack of knowledge of what would happen to their child during the procedure. Many of the parents wanted a 'guarantee' of success from specialists for surgical interventions, and were reluctant to go ahead with it otherwise. Lack of understanding of treatment options (or lack thereof) and rehabilitative approaches required in certain conditions also led parents to explore multiple treatment options, moving them into debt, forcing them to sell assets, making them cynical and resisting any further treatment.

*"As we are illiterate, we don't have any knowledge about health or such diseases. but we sold five acres of my land for my child's surgery.. but he has still not recovered fully...I don't know what to do.. "*

- Father of a 15 year old male child having neural tube defect, Kalaburagi, Karnataka

Further, lack of awareness regarding treatment options, length of treatment for children with 2Ds also posed a barrier for rural families having to go to a large city for treatment. Here, the anxiety and unfamiliarity of venturing outside their surroundings, and going to a large and crowded health facility with unfamiliar and complex administrative processes, was a source of fear for them. This was particularly true for tribal communities of Tripura and Meghalaya who lacked the necessary exposure of living in a city.

### **Psychological distress as a function of constant caregiving among primary caregivers (mothers)**

Another common challenge faced by caregivers that often goes unaccounted for as a barrier is the emotional burnout among the primary caregivers. Traditionally, women have been attributed primary responsibility for family work in the Indian context. This is especially true of the rural context, where the

mothers usually assume ultimate responsibility for parenting and often, carry the 'triple burden' of taking care of children with 2Ds, earning money either through self-employment options (home-based options), alongside juggling domestic chores such as regular cooking and caretaking of other children. In certain cases, a few of the women respondents also alluded to the violence inflicted upon them by their spouses

In addition, children with special needs often require round-the-clock and dedicated care. As observed in a few conditions (under RBSK), children are unable to perform routine activities on their own or require constant monitoring. A large proportion of these caregivers are unable to attend social functions or other events due to the constant care and attention required to raise children with special needs. This has resulted in social exclusion and the lack of a personal life outside of their children for primary caregivers. They often suffer from 'caregiver stress', resulting from the fatigue, emotional stress and strain that comes from being a primary caregiver. This is exacerbated in situations where caregivers receive limited support from their family members or the community. They lack social support groups that could serve as a forum to discuss pertinent emotional issues, such as feelings of frustration, child-rearing problems and management of children with special needs. Typically, these caregivers have also exhausted all treatment options and have tried everything – right from medical care, Ayurveda, to village doctors / traditional healers, to divine interventions, etc.

*“..I have to even think when he is going to be hungry and feed him accordingly... I also have to clean after he urinates and defecates... there is no one to help me...I am alone.... Even my husband doesn't do anything....I have even attempted to kill myself 2 times...”*

- Mother of a 13-year old male child with multiple disabilities, Raichur, Karnataka

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*All the barriers interact with one another in unfavourable ways to widen the disparity in access to healthcare for caregivers of children with 2Ds. Given that 37% of these caregivers interviewed were BPL families, it further exacerbated their access to care*

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## Enablers

It is important to understand factors that would enable and motivate caregivers to avail RBSK services, as these can be leveraged to improve service utilisation. Enablers were understood both by directly asking caregivers what would enable them to overcome their barriers, as well as by identifying enabling factors from a supply-side perspective that facilitate better health seeking behaviour among caregivers.

### ***Building awareness of RBSK and the importance of early intervention***

The majority of respondents stated that they would get the required medical intervention if a doctor advised them to do so. This highlights that there is a need among most respondents to receive medical advice from a trusted source, namely a doctor, in order to overcome their cognitive barrier. Leveraging medical officers (doctors) to serve as a motivating force for caregivers would thus be beneficial in raising awareness of the importance of medical treatment, and in particular, early intervention.

Another common response among caregivers regarding enablers was that the government should provide support for such children, through financial assistance or schemes. This again demonstrates a low awareness among respondents about the programme itself, and a need to adequately address this. It is imperative to underscore that such a programme is in-place to minimize disabilities, and to improve quality of lives of children born with defects or having developmental delays through screening and intervening early. Further, building awareness around free management and treatment for children with

2Ds could be useful in further generating demand among caregivers. Emphasizing treatment is free could also serve to partly address financial barriers, as a large number of caregivers do not know this.

In addition, caregivers could also be provided messaging on preventing birth defects during adolescence, pre-conception care, and pregnancy by potential integration and convergence with related programmes such as RSK (adolescent health programmes) and other maternal health programmes.

### Other health insurance programs

In states such as Maharashtra and Karnataka, complementary health insurance schemes that also cover RBSK conditions have been extremely beneficial in addressing financial barriers. Schemes like Rajiv Gandhi Jeevandayee Arogya Yojana (RGJAY) in Maharashtra and Vajpayee Arogyasri in Karnataka offer financial support for treatment and surgery for certain conditions identified through RBSK. Beneficiaries can avail these services at empanelled government and private hospitals. These have been successful in alleviating the financial burden on caregivers, and have further increased their willingness to avail treatment.

### Transportation to health facilities

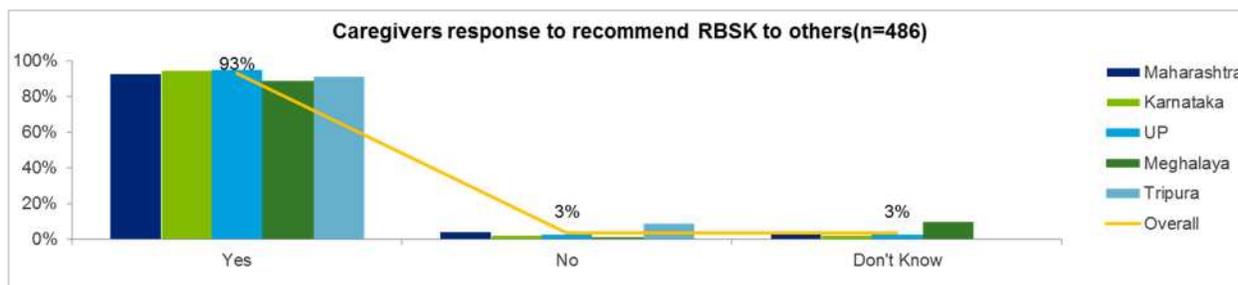
As transport to health facilities for treatment is a major barrier for caregivers, mechanisms that address this serve as critical enablers for the programme. This is currently being done through:

- Health insurance schemes such as Vajpayee Arogyasri that also include a travel and dearness allowance,
- Systematic referral and evaluation system followed in Uttar Pradesh where MHTs spend one day a week transporting patients to health facilities instead of conducting screening activities. The latter is further beneficial as MHT staff often subsequently help patients navigate the processes at the health facility, ensuring they do not face any difficulties or obstacles.

Introducing a mechanism wherein transport to health facilities is covered or provided, either through RBSK itself or other health programmes including ambulance services once a week, would serve as a very strong enabling factor for referral and evaluation.

### Creating a positive experience with the programme for patients and families

**Exhibit 23: Caregivers response on spreading awareness about RBSK**



Findings from the study indicated that, 93% of the caregivers who were aware of RBSK would recommend it to others. As was expressed by a number of community members, 'word of mouth' could potentially serve as either a strong motivator or as a deterrent in rural communities – satisfactory treatment received by one family can encourage others to go to a health facility, while poor quality treatment can dissuade others from accessing the health facility. In this context, steps such as ensuring

patients are being referred to the right facility with adequate infrastructure and trained medical officers to receive these beneficiaries can go a long way in ensuring these families return for repeat visits. Additionally, increasing the number of DEICs so that all services are offered in a single location, and introducing a helpdesk or a kiosk to help patients navigate complex health facilities, etc. are crucial. These can help ensure a positive experience for caregivers and their children who avail treatment, and serve as a motivator for subsequent caregivers to access treatment.

In addition, a few respondents expressed a need for better facilities and better availability of physicians/specialists at government hospitals. While this points towards a larger need for systemic improvements in the government health system, it also emphasizes a dissatisfaction with their experience and a need to improve it.

## A tale of two caregivers

### A Ray of Hope

Vanlalhruaia (name changed) is the father of a 4 year old child in Dhalai, Tripura. His son, Samsona (name changed), was born with a cleft lip. As it was a home delivery and the mother's access to regular antenatal care had been poor, the family did not know the reason behind the birth defect, or how it could be cured. Despite being aware of the condition since birth, the family was unable to take any concrete steps towards healthcare in the initial years due to a lack of financial resources.

Part of the Reang tribe of Tripura, the family eventually took Samsona to a nearby missionary hospital for treatment, where they were able to get treatment for 50% of the cost. They were, however, only given basic medicines and no further help. Living in a remote village in Dhalai with tenuous ties to the formal health system, they felt hopeless in their situation and were grappling with a lack of options.

Last year, they received support from the Anganwadi Worker in their village, who told them about RBSK screening visits at the nearby Anganwadi Center, and called them to the Center on the next screening day. The RBSK MHT screened Samsona and referred him to Tripura Medical College in Agartala for surgery. One member from the MHT accompanied them to Agartala, and helped them with the initial registration and navigation at the hospital. For two days, while Samsona was admitted in the hospital, his father remained in Agartala, staying at the government guest house that provides accommodation for families of RBSK patients. He did, however, have to cover his own food expenses, but incurred no other expenses. When Samsona was discharged, the MHT also brought them back to Dhalai in their vehicle.

Samsona's family is very satisfied with their experience with RBSK, and continue to recommend it to others in their village.

### ***Journey of Disappointment***

Parvati (name changed) is the mother of Nithin (name changed), a 6 year old child in Kalaburagi, Karnataka. She had known since a few months after his birth that her child is different: he was slower to sit up and crawl than other children his age. She only learnt of the medical diagnosis last year, during a screening visit by an RBSK MHT at the Anganwadi Center, when he was diagnosed with Down Syndrome. She feels it is due to her consanguineous marriage: she is married to her maternal uncle.

Since Kalaburagi has no DEIC, the MHT referred them to the closest CHC, a few kilometres away. Nithin's father spent Rs.500 transporting him to the CHC, also losing out on a day's wages in the process. At the CHC, after waiting for several hours, they were told that the CHC did not have the resources to handle their case, and they should go to the Kalaburagi District Hospital instead.

Nithin's father took him to the DH a few weeks later, incurring considerable transport expenses and wage loss again. At the DH, they found long queues for registration and no doctor to attend to them for a few hours. The doctor, when they were finally able to meet him, told them that the treatment for Down Syndrome would be long, and Nithin would have to receive 5 growth hormone injections over the course of one year, each priced at INR 14,000.

The family paid for two growth hormone injections over three months, having to make lengthy trips to the DH in the process. Finding little improvement in Nithin's condition, and being increasingly unable to afford the injections, they were left extremely dejected and frustrated. They finally decided to stop the treatment, instead of completing the course.

# Chapter 3b: Key Findings for Other Stakeholders

## Key Takeaways:

### KABP summary for Informal Health Providers, Head teachers, Mothers-in-law and Formal and Informal groups

Aspects	Informal Health Providers (IPs)	Head Teachers	Mothers-in-law	Formal and Informal groups
<b>Knowledge</b>	Aware of children having 2Ds, and have examined such children who came to them for treatment; Unaware of RBSK and the services it offers	Have a limited understanding of RBSK; Possessed awareness of other state health insurance schemes and SSA's IE Programme	Unaware of RBSK and its services; Aware of the child's condition usually only when it is a visible defect	Aware of the programme; some displayed in-depth knowledge of the continuum of care covered under the programme, from screening to treatment
<b>Attitudes</b>	IPs have a positive 'curative' attitude towards children with 2Ds, and feel that they can be treated with Western medicines	Show sympathy and care towards the children with special needs that they have in their schools, usually give them greater attention	The response to learning about the child's condition centered on worry and concern for the long-term care and future of the child	It varies from supportive behaviour to discriminatory, try to instill positive attitudes e.g., teachers and school children encouraged to behave positively
<b>Beliefs</b>	Range of beliefs regarding the child's condition, from myths and God's wish to poor eating habits during pregnancy; Have faith in the medical system for such children, especially for surgical interventions.	Feel that such children are slower to pick up in the classroom and forget faster, but with due care, can excel in non-academic fields; Feel that children with 2Ds can be cured completely with early intervention	Beliefs for the cause of the condition ranged from God's wish and fate to poor antenatal care and inter-relation marriages; Positive attitude towards medical treatment, but uncertainty around surgery continues	Feel that a programme like RBSK is beneficial, especially for low-income families; Beliefs regarding causes centered less on myths etc., and more on antenatal care, hereditary causes etc.
<b>Practices</b>	Provide treatment to children with 2Ds in the form of Ayurvedic medicines, and sometimes in the form of mantras and prayers; When surgical interventions are required, typically refer children to health facilities	Give special attention to such children, through special classes, extra motivation, and sometimes, academic concessions; Some also provide counseling to parents and information on health camps	Proactive in choosing medical treatment over others; preference tends to be towards the private health sector; Somewhat involved in health decision making for the child; more so in the case of grandsons	Not currently very heavily involved in the programme; Expressed that they could be involved by supporting and counselling caregivers, providing information on government schemes, etc.

Key demand- and supply-side stakeholders including informal health providers, head teachers, traditional healers, informal and formal group members (GP/SHG and SDMC members), frontline workers, mobile health teams, were interviewed during the course of the study, through both IDIs and FGDs, to ascertain their knowledge, attitudes, beliefs, and practices regarding RBSK and children with 2Ds. The key findings of these interactions are summarised below.

## Informal healthcare providers

### Profile and role

It is common practice for rural households in developing countries, including India, to rely heavily on informal healthcare providers (IPs). This network of informal providers often serves as a substitute for the formal health system. While there is no universally used definition of informal healthcare providers, the definition being used for the purpose of this study is providers who have not received formally recognized training with a defined curriculum from an institution. Additionally, IPs meet at least two of the three criteria below<sup>32</sup>:

- IPs are usually paid by patients not institutions, and in an undocumented, cash-based form
- IPs are not typically registered with any government licensing or regulatory body
- IP professional associations, if any, are usually not focused on regulation but more on business activities

In the Indian context, IPs generally include the following: compounder, drug vendor, non-graduate medical practitioner, non-registered healthcare provider, quack, rural medical practitioner, semi-qualified provider, alternative health provider, ayurvedic doctor, alternative healer, traditional healers, village doctors, private doctors (non-registered), informal community health workers and traditional birth attendants.<sup>33</sup>

### Profile of informal service providers (IPs)

Most of the IPs met have received at least basic level school education. Many have been practicing for the past 30 years or more. Most of them had not received formal medical training, but instead have been trained by previous generations and are continuing a family tradition.

Patients who come to these providers typically consult them for a range of ailments, from basic conditions such as fever and diarrhoea to more serious ailments such as blindness, mental retardation, snake bites, issues during pregnancy, paralysis, etc. Such Patients choose to go to an informal provider instead of the formal health system for a variety of reasons. A few common reasons are below:

- It is a cheaper option, as IPs are closer and more easily accessible, allowing patients to save on transport cost of traveling to a health facility. Additionally, since IPs usually charge nominal amounts, patients are able to save on treatment and medicine costs

*“Parents of these children cannot afford to go to CHC and PHC, due to which they have come to me for the treatment. They cannot pay for the transportation to the facility, they cannot even*

<sup>32</sup> Sudhinaraset M, Ingram M, Lofthouse HK, Montagu D (2013) What Is the Role of Informal Healthcare Providers in Developing Countries? A Systematic Review. PLoS ONE 8(2): e54978. doi:10.1371/journal.pone.0054978

<sup>33</sup> Sudhinaraset M, Ingram M, Lofthouse HK, Montagu D (2013) What Is the Role of Informal Healthcare Providers in Developing Countries? A Systematic Review. PLoS ONE 8(2): e54978. doi:10.1371/journal.pone.0054978

*spend money buying medicines...they often pay me in kind, a bag of rice or grains...sometimes, they cannot even pay me in-kind...I am running my practice to serve these communities.. ”*

- Traditional Healer, Dhalai, Tripura

- It is an easier and more convenient option as compared to government hospitals, which are over-crowded and have long wait times
- There is often greater trust in traditional healers than formal health workers, as they usually belong to the same community
- Caregivers often turn to faith-based treatment when medical treatment has not had any tangible beneficial impact on the child's health

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*In the North-East, going to an IP is a more common practice as they usually belong to the same tribe and speak the same language as the patient, while formal health workers are considered outsiders and not trusted. This is further exacerbated by the terrain and accessibility issues of reaching a health facility, thus making it easier to go to a nearby traditional healer instead*

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## Key findings from primary interactions

### Knowledge

With respect to knowledge among IPs, most were aware of children having birth defects and development delays in their communities, and reported having such children come to them for treatment. However, most IPs met were unaware of RBSK, its benefits and the services it offers.

### Attitude

IPs had a positive attitude towards children with 2Ds, and feel that they can be treated with Western medicines. They continue to encourage parents and community members to seek medical care.

*“Whenever a child with club foot, or cleft lip comes to me, I tell them this cannot be treated with herbs or my medicines... I tell them that they should go to a big hospital or a government health facility to get treatment done.... I only treat minor ailments like cold, cough, fever, etc.”*

- Alternative health provider, Jalna, Maharashtra

### Beliefs

IPs had a range of beliefs surrounding why children have 2Ds. Some believed in myths and reasons beyond human control, such as it being destined or God's wish. In such cases, they believed that there is no cure and nothing can be done to help the child. However, there are enough IPs who also believed that children were born with a certain condition due to reasons that are in their parents' control, such as poor eating habits during pregnancy, inadequate antenatal check-ups, poor nutrition and health-related habits during early years of the child.

*“Some pregnant women do not have adequate nutritious food due to which they end up having a child with birth defect or development delay”*

- Traditional Healer, Barabanki, UP

Despite knowing about their child's health condition, rural families choose not to avail treatment. Respondents felt that this was owing to the fact these tend to be uneducated or semi-literate, and have poor understanding of the conditions, and do not know the importance of intervening early. Often, parents are unable to provide sufficient attention to their children as they are daily wage labourers and do not have enough time to devote to the child.

An interesting finding, which came out through this study is that, all the IPs interviewed have faith in the medical system for such children, especially when surgical interventions are required.

### Practices

IPs provide treatment to children with 2Ds in the form of ayurvedic medicines, such as ointments, powders, or pastes derived from herbs. Some also provide treatment in the form of mantras and prayers. However, when surgical interventions are required, IPs typically refer children to health facilities, both government and private.

### How they can be leveraged

As IPs tend to be a trusted point of contact for the community, including caregivers of children with 2Ds, there is huge scope to leverage them to improve uptake of RBSK. IPs can be trained by the Government to screen for the conditions covered under RBSK, and appropriately refer their patients to health facilities. As trusted members of the community who do not have formal medical training, they can play a similar role in the programme as ASHAs do. In addition, since they represent a large and heterogeneous provider category, this training would have to be restricted to a section of providers who the Government is willing to train; in particular, the IPs whose practice is rooted in medically sound and acceptable techniques.

This is in line with the findings of the primary interactions, which revealed that most of the IPs interacted with during the study, after learning about the services and benefits of RBSK, were open to receiving formal training on the programme.

## Head teachers

### Role

Head teachers play a key coordinating role within RBSK. As a result of their regular contact with parents, they serve as a vital link between the Mobile Health Teams and parents of children who have screened positive for a 2D.

### Key findings from primary interactions

#### Knowledge

Head teachers interviewed were aware of RBSK, to the extent of knowing that “a team of doctors comes in a vehicle every year and screens children for some defects/delays”. However, they were unaware of the details of the programme, including the process and protocol following the screening, for a child who has been screened positive. A few teachers still thought of RBSK as being an extension of the erstwhile School Health Programme. Some respondents were aware of RBSK card that is given to the school for each child, but are not involved in follow-up and thus do not have additional information regarding the treatment of the children concerned.

Further, most head teachers are aware of State government health schemes such as Vajpayee Arogyashree in Karnataka and NGOs working in the space such as Operational Smile. In such cases, teachers provide information to parents about these schemes and programmes. Most of them are also aware of the Inclusive Education (IE) programme under SSA, through which aids and appliances are distributed to disabled children during camps. They are also aware of the home-based education that is offered under Inclusive Education, and provide related information to parents of children who are unable to attend mainstream schools. For most parents of children with disabilities, special/itinerant/resource teachers under Inclusive Education serve as the first-point-of-contact, providing relevant information about the programme including details on health camps.

#### Attitude

In the context of attitude towards 2Ds, most teachers showed sympathy and care towards the children with special needs that they have in their schools, usually giving them greater attention.

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*The attitudes of other school children towards such children, however, vary. In North East India, where communities tend to be more inclusive on the whole, little or no discrimination is displayed towards these children. Other children offer help and support to children with special needs, helping them with routine activities such as holding their bags, etc.*

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#### Beliefs

With respect to beliefs, most caregivers felt that the learning curve for children with 2Ds is different from that of others, and as a result they are slower to pick up and forget faster. However, they feel that with due care and focus, such children have great potential to excel in non-academic, creative fields such as dancing, singing, painting, etc. Further, many of them felt that children with 2Ds can be cured completely with early intervention. They thus feel that programmes like RBSK are essential for such children, especially for families who would not otherwise have been able to afford treatment.

## Practices

Teachers usually give special academic attention to children with 2Ds, by organising special classes and motivating and encouraging the children to perform at par with the other students. In some schools, special considerations are made for such students, and academic concessions are given in discussion with teachers following exams. In such cases, teachers also take care to ensure that academic concessions do not interfere with ensuring that children are motivated to do their best.

*“there are some special children in our school, we treat them like other normal children only. We take care of them as per the instructions given by their parents”*

- Head Teacher of a school in Etah, UP

Outside the classroom, some well-informed teachers also provide counselling to parents of children with 2Ds and information regarding health camps and treatment options.

## How they can be leveraged

Many teachers mentioned that one of the major challenges faced by caregivers of children with 2Ds is poor understanding and information on the child's condition and treatment options available. Caregivers require a trustworthy source of information and counselling, and there is potential for teachers to play this role, as parents are in regular contact with teachers and thus have faith in their advice.

As mentioned previously, some teachers are already playing this role, but in a more informal way and solely based on their personal levels of commitment. There is a need to institutionalise this role for teachers in a more formal manner, wherein they are involved in mobilising parents, from ensuring that their children attend school on screening days to providing information on treatment options and encouragement to access care. Teachers are positioned to play a crucial role in generating awareness on RBSK services and the importance of early intervention among parents.

Further, many teachers met felt that a programme like RBSK is important and beneficial for children with 2Ds, there would be a willingness among teachers to be involved in improving programme uptake through awareness generation and information dissemination. The primary challenge in teacher involvement, however, is that they are already over-worked and might be reluctant to devote additional time to a programme that is not technically under their purview. Thus, there could be a need to introduce incentives or some other mechanism to motivate teachers to increase their involvement in RBSK.

## Mothers-in-law

### Role

Mothers-in-law can play a critical role in being either a motivating or an impeding influence on the parents availing treatment for their children.

### Key findings from primary interactions

#### Knowledge

Most of the mothers-in-law were unaware of RBSK and its services. Regarding awareness of a child's condition, it tends to be higher when the child is suffering from a more tangible condition that can be visually detected, such as club foot. When the child is suffering from a condition that has no external manifestation or takes some time to manifest, such as CHD or neuro motor delay, awareness and understanding of the details of the condition tend to be low. While families are usually aware that the child is different from others his or her age, it is only when the family consults a doctor that they understand the nature and details of the condition.

*“My granddaughter needs surgery. Before 2013 we did not know about her having a heart problem.... it was hidden.....”*

- Grandmother of a 10-year old girl child with CHD, Jalna, Maharashtra

#### Attitude

The response to learning about the child's condition, for most mothers-in-law, centred on worry and concern for the long-term care and future of the child. They felt that the community was typically supportive and sympathetic, and often provided guidance and advice to the parents regarding treatment for the child. Some of the respondents felt, however, that front line workers were less supportive. They provided advice to the extent that treatment should be availed, but often failed to offer tangible details such as where to go for treatment or information on government health schemes.

#### Beliefs

Mothers-in-law had wide ranging beliefs surrounding the reason behind the child's condition. While some believed it was due to external reasons such as God's wish or fate, others felt it was due to reasons such as poor antenatal care taken by the mother, inter-relation marriages, and premature delivery of the child. Additionally, some respondents did not know the reason behind the condition.

Regardless of the belief, most respondents had a positive attitude towards medical treatment, believing that medical intervention is capable of curing the child completely. However, there continues to be hesitation and uncertainty surrounding surgery and its side effects or outcome.

#### Practices

Families are proactively tending to choose medical treatment over others. While a few respondents stated having tried traditional healers or faith-based treatment, most took their child with special needs to health facilities, ranging from government and religious trust hospitals to private facilities. While the preference tends to be towards the private sector, in expectation of better quality and shorter wait times, the family's economic status is the primary determinant of health facility type. The preference for private facilities is also stronger in the case of more serious ailments, with families turning to government healthcare or home remedies for simpler ailments like coughs and fevers.

Further, it was observed that, Mothers-in-law are involved to an extent in decision-making regarding treatment of the child, and more so in the case of grandsons as compared to granddaughters. However, final decisions regarding the child's health are taken by the parents.

### **How they can be leveraged**

Mothers-in-law's influence in the health of their grandchildren appears to be limited. However, they can be leveraged by RBSK to serve as an encouraging force for parents, motivating them to avail treatment for their children.

## Formal and informal groups

### Profile and role

Formal and informal groups in the community include members of Gram Panchayats (GP), Self-Help Groups (SHG), Mothers Groups (MG), Village Health and Sanitation Committees (VHSC), and School Development and Management Committees (SDMC). These groups, as representative of the larger community, provide important insights into community perceptions and can play a key influencing role in the society.

### Key findings from primary interactions

#### Knowledge

Most respondents were aware of RBSK, with a few (especially members of SDMCs and SHGs) displaying in-depth knowledge of the continuum of care covered under the programme, from screening to treatment. A few even described success stories of surgeries conducted through RBSK in their community.

#### Attitude

Respondents had varying descriptions of community attitudes and behaviour towards children with 2Ds, ranging from supportive behaviour especially from educated community members to discrimination and name calling. The attitudes of respondents themselves were largely positive, with most stating that since such children are members of the community, they should not be treated any differently. Some felt that they should, in fact, be given greater care and attention. Further many of them, tried to instil this positive attitude towards such children among the community. A few members of SDMCs, for example, mentioned that they instruct and encourage teachers and children in schools to behave in a positive and supportive manner towards children with 2Ds.

#### Beliefs

Most respondents believed that a programme like RBSK is extremely beneficial, especially for low-income families who would not otherwise be able to afford treatment. They feel that caregivers, if aware of the programme, would choose to avail treatment for their children. Further, they had a range of beliefs surrounding the causes of 2Ds. Interestingly though, most beliefs did not relate to myths and superstitions but instead centred on modifiable behaviours and practices. A few commonly mentioned beliefs include:

- Improper antenatal care, such as improper diet, not consulting doctors or frontline workers, not getting diagnostic tests done, and not taking the correct nutritional supplements
- Lack of clean and sterile environments during childbirth and after
- Instances of domestic violence, exposure to x-rays, intensive manual labour, or accidents during pregnancy
- Genetic and hereditary causes

#### Practices

While respondents do not currently seem involved in the programme, they expressed that they could be involved in a number of ways, including supporting and counselling caregivers, providing information on government schemes, and providing financial assistance through community mobilisation in some cases.

They were also useful in describing health-seeking behaviours of caregivers of children with 2Ds. Corroborating the responses given by caregivers, interactions with GP members, SDMC members and SHG members revealed that consulting an informal health provider is increasingly becoming less

common, with caregivers choosing to go to the formal health sector. While there is a preference for private health care, the financial status of the family is the primary determinant of the type of health facility visited. According to these respondents, families tend to be proactive in seeking care, and often turn to frontline workers for advice on where to go for treatment.

### How they can be leveraged

During these interactions, the respondents themselves expressed a need for the programme to be strengthened by involving community members to raise awareness of RBSK and its benefits, especially among affected families. This demonstrates both a need and willingness among these community members to be involved in improving programme uptake.

Members of formal and informal community groups can be leveraged for community mobilisation activities, to spread awareness of the programme and encourage caregivers of such children to go for follow-up visits and rehabilitative care. As key influencers in the society, these groups are in an ideal position to play this role in supporting the programme and motivating the community.

Further, these groups can also act as a social support network, which is often missing from the lives of parents of children with conditions requiring protracted care (including developmental delays, disabilities).

Going one step further, these groups could perhaps also serve as a liaison between the health system and caregivers, playing a facilitating role in connecting caregivers to the appropriate health workers and facilities when required. These groups could also play a role in providing tangible support to families, for example, by organising small community loans or bringing people together to form support groups.



# Chapter 4a: Key Findings for Health System Functionaries

## Key Takeaways:

### RBSK Overview

- RBSK had a staggered launch in different study states, from April 2013 in Maharashtra to April 2014 in Meghalaya. Due to operational challenges in recruiting human resources, there were also delays in terms of actual roll-out of the programme
- In all five states, screening has only been initiated in schools and Anganwadi Centres; home-based screening and screening in delivery points is yet to begin (as of Jul 2016)
- Although most the states have MHTs in place, the actual composition of MHTs is varied for different states, based on availability of manpower and the state context
- Challenges faced by MHTs include limited IPC and soft skills for MHTs to deal with parents of children with 2Ds, limited competency to screen for developmental delays, high daily screening targets, resistance from the community, limited ability to help caregivers of children beyond screening
- Few good practices enabling better implementation of RBSK in the study states are:
  - Use of WhatsApp groups by MHTs to share knowledge on a larger platform
  - Use of complementary state health insurance schemes to fund treatment of several conditions listed under RBSK, especially those involving surgeries
  - In some states, MHTs are involved in transporting and accompanying group of families to PHCs/CHCs/DHs for treatment
  - In Tripura, a camp-based approach is used for treatment of certain conditions

### KABP summary for Mobile Health Teams and Front Line Workers

Aspects	Mobile Health Teams	Front Line Workers
<b>Knowledge</b>	Aware of RBSK , and its role in minimizing disabilities through early intervention	Aware of basic programme details, however most are unaware of larger programme details or objectives, and have not received any formal training
<b>Attitudes</b>	All MHT members had a very supportive attitude towards children with 2Ds, they felt that RBSK is beneficial as it serves the needs of the low-income families having children with 2Ds	Most frontline workers are supportive and sympathetic towards children with 2Ds,generally they support parents of children with 2Ds by counselling and advising them to avail treatment for their children
<b>Beliefs</b>	Range of beliefs including consanguineous marriages, maternal age, poor nutrition and lack of rest/care during pregnancy, poor ANC check-ups, lack of immunization, etc.	Most respondents felt that 2Ds were caused due to genetic disorders, consanguineous marriages, and poor antenatal care during pregnancy, etc. Many shared early intervention is essential, and can be beneficial in minimizing disability
<b>Practices</b>	Practice varies across MHTs- a few teams follow-up personally, while a few conduct a weekly evaluation camp at PHCs, a few track parents who come to DEICs, etc.	ASHAs have a limited role in RBSK delivery, especially since home-based screening for newborns has not been rolled-out. AWWs play a role in mobilizing children for screening

This chapter includes two main sections: -

- Findings on programme implementation including human resources, infrastructure, screening and referral, programmatic training, communication efforts (IEC and branding), perceptions of supply-side functionaries, and concludes with innovations and based practices. There are primarily based on interviews at National, State, District and Block-level government officials from the Health Department.
- Findings from interactions with MHTs and FLWs including knowledge, attitudes, beliefs and practices of children with 2Ds.

## Programme overview

RBSK was launched at different times in the five states, as early as April 2013 in Maharashtra to April 2014 in Meghalaya. For the latter, rollout was delayed due to State and National elections. The table below summarises when the programme was launched in each state, and the reach of the programme.

**Table 8: RBSK overview**

	Launch	MHTs in place	# of districts programme is present in
<b>Karnataka</b>	April, 2013	402	30
<b>Maharashtra</b>	April, 2013	1,171	34
<b>Meghalaya</b>	April, 2014	78	11
<b>Tripura</b>	February, 2014	22	8
<b>Uttar Pradesh</b>	December, 2013	1,548	75

## Screening of newborns at delivery points and ASHAs is yet to roll-off

In all five states, screening has only been initiated in schools and Anganwadi centres by MHTs, with home-based screening by ASHAs and screening in delivery points by MOs yet to begin. In Uttar Pradesh, however, only screening of the 3-6 year age group in the Anganwadi category is taking place. Screening for the 0-3 year age group is expected to start later in 2016.

Most states are following the screening protocol provided in the guidelines, with screening visits to government and government aided-schools once a year, and visits to Anganwadi centres twice a year, typically during school holidays. In a couple of districts (including Kalaburagi, Karnataka and Aurangabad, Maharashtra), some private schools have also been included for screening under RBSK, if they have specifically requested it from the government.

In addition, most government officials at the district level received RBSK training at the state when the programme was first launched. In the case of two districts in Karnataka (Raichur and Dharwad), however, this training was not provided, as the two districts were not invited to the state level training.

One thing to be highlighted for Maharashtra is that, there is a parallel operational structure in place for healthcare delivery, with the programme being delivered by the Civil Surgeon for DHs, Sub-Divisional Hospitals, and Rural Hospitals, and the District Health Officer for PHCs. This dual structure has resulted in several administrative and coordination issues that impact effective implementation of RBSK.

## Mobile Health Teams

While the MHT composition according to the guidelines is 2 AYUSH doctors (one male, one female), 1 ANM or staff nurse, and 1 pharmacist, the actual composition has varied for different states, based on availability of manpower and the state context and nuances. Additionally, a few districts have teams with MBBS doctors instead of AYUSH doctors, depending on availability and ease of recruiting. The table below summarises the MHT composition for the study states.

**Table 9: Composition of MHTs across different study states**

	Composition
<b>Karnataka</b>	1 MO, 1 LMO, 1 SN/ ANM, 1 Optometrist
<b>Maharashtra</b>	1 MO, 1 LMO, 1 ANM, 1 Pharmacist
<b>Meghalaya</b>	2 LMOs, 1 ANM, 1 Pharmacist/Lab technician
<b>Tripura</b>	1 MO, 1 LMO, 1 ANM, 1 Pharmacist
<b>Uttar Pradesh</b>	1 MO, 1 LMO, 1 ANM, 1 Optometrist

*In Meghalaya, cultural differences make it easier to recruit female doctors than male doctors, resulting in MHTs consisting of two lady MOs. Additionally, in a few districts (including West Khasi Hills and Garo Hills), MHTs include dentists instead of AYUSH, as they are more easily available*

Recruiting is typically done at the district level; however, it takes place at the state level in Maharashtra. After recruitment, MHTs receive five day orientation training at the state level. All teams in states and districts visited, apart from in Uttar Pradesh, have received this training. In Uttar Pradesh, even though the programme has been operational since 2013, none of the MHTs across the state have received the five-day training.

### MHT-specific operational challenges

#### Training on RBSK to MHTs at all states except UP

RBSK training to MHTs has been rolled out in all study states except in Uttar Pradesh. This is a major impediment in delivery of the programme, as they have been conducting screening based on their own understanding of RBSK conditions and informal training provided by district/ block officials. This is particularly challenging in screening for development delays, which tend to be more difficult to identify. MHT members themselves referred to their discomfort in identifying developmental delays without rigorous training.

#### Lack of focus on IPC and soft skills during training

Training programme of MHTs does not include interpersonal communication training, soft skills training. This is especially critical in helping MHTs effectively communicate the implications of the health condition and the importance of early intervention to parents of children screened with a 2D. Further, RBSK does not have a regular refresher training for MHTs that is important to improve service delivery and sharpen the skills of AYUSH doctors.

### **Retention of AYUSH doctors a challenge in few states**

Several states face challenges in recruiting and retaining AYUSH doctors. Such challenges are exacerbated in states like Meghalaya and Tripura, due to the remote and inaccessible terrain. Additionally, low salaries also serve as a de-motivator for MHT, especially in Maharashtra. In Meghalaya, for example, AYUSH doctors are paid less under RBSK as compared to other health programmes, making it difficult to attract them. In addition, Meghalaya has fewer colleges offering AYUSH degrees making it further difficult to recruit locally.

### **Poor conducive environment for MHTs**

In some states, facilities such as separate office space, stationery, and laptops are not provided to MHTs. This is especially challenging for data entry. In Uttar Pradesh, for example, manual data entry has led to data discrepancies and delays in reporting data. Vehicles are also often shared between multiple MHTs, resulting in time inefficiencies. Due to budgetary constraints, MHTs are forced to hire vehicles such as TATA Magic, which are inconvenient for long-distance travel, particularly on bad roads. Further, in some states (such as Meghalaya), some MHTs were observed to be hiring vehicles on daily basis and then seeking a reimbursement which was often delayed.

### **High daily targets affect quality of screening**

MHTs are typically given daily targets for screening, which range from 100 to 150 children. Setting of such targets tends to affect quality of screening, as MHTs are more focused on conducting quick and superficial screening to achieve these numbers than ensuring quality screening. This often even results in manipulation of numbers for reporting.

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*In states such as Tripura and Meghalaya, the terrain makes achieving these targets especially challenging, as schools and AWCs are often in inaccessible locations, where it takes MHTs longer to reach. This significantly lowers daily screening numbers*

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Due to the limited time spent with each child during screening, and due to MHTs' weak understanding in identifying developmental delays, screening for developmental delays is a challenge faced by MHTs across study states.

### **Screening at AWCs is challenging**

AWC screening is more challenging due to a variety of reasons mentioned below:

- Lesser registration and attendance numbers in AWCs make it more challenging for MHTs to achieve their targets; as a result, they have to visit a larger number of AWCs each day to meet their targets, which is more time intensive on travel
- AWCs are open for a shorter duration in the day as compared to schools, reducing time available for screening
- Screening is more challenging and unstructured for MHTs, since the children are younger and all children arrive for screening along with their caregivers at the same time. In schools, on the other hand, screening is conducted in a more organized, class-wise manner

### **Some Mobile Health Teams tend to face resistance from the community**

During screening, MHTs often face resistance and distrust from the community. This builds up especially during the second visit to the same community, as community members feel that the doctors only screen and do not provide medicine or treatment. As a result, MHTs often find it challenging to build faith in the community or communicate effectively with parents.

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*Lack of faith in MHTs (and public health system) is a bigger challenge among tribal communities of North-Eastern states such as Meghalaya and Tripura, where communities tend to not trust those outside their tribe. Language barrier is also often an issue in such cases*

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### **Weak understanding of RBSK among public health functionaries**

Several states have a weak referral system to evaluate and manage children screened to have 2Ds. In the absence of DEICs, children are often referred to PHCs/CHCs/District Hospitals. It was observed that the medical officers concerned in these facilities do not possess the complete understanding of RBSK and its associated health conditions. This could be due to the lack of training or orientation of the health system functionaries at the regular health facilities. They often do not communicate clearly with the parents on the course of action appropriate for the child, duration and necessary procedures, etc. Parents often have to spend long waiting times at the facility, face overcrowded facilities and do not get the dedicated attention and knowledge on future course of action/treatment.

### **Public health facilities is not sufficiently geared up to receive the parents for follow-up and care**

It was found during the study that, most of the public health facilities lack the necessary diagnostic facility to perform the evaluation and treatment, often requiring parents to go to private sector diagnostics resulting in huge out-of-pocket expenditure for parents. Instead of experiencing the necessary care and free treatment, parents are often subjected to physical and financial stress both due to repeated visits, lack of clarity on the visits required and future course of action, further reinforcing their mistrust in the public health system.

Further, it was found that, none of the states with the exception of Maharashtra and Tripura have signed MoUs with private sector players for diagnostics and tertiary care services. Even in states such as Maharashtra, there is a reliance on diagnostic camps such as 2D Echo camps for confirming the congenital heart diseases leading to sometimes, 2-3 months waiting period for diagnosis and confirmation.

### **Delays in setting-up and operationalizing DEICs is a barrier to uptake of RBSK, especially for follow-up and care**

Interactions with supply-side officials highlighted that the respective state governments are not very serious about expediting the set-up of DEICs. Despite three years since the launch of RBSK, the pace of operationalization of DEICs have been quite slow, the DEIC status of the five states is summarized in the table below:

**Table 10: Status of operationalization of DEICs in the five states**

States	DEIC status
<b>Karnataka</b>	1 operational DEIC in the state (DEIC Mangalore); 4 to be operational by June 2016
<b>Maharashtra</b>	8 sanctioned DEICs; 2 DEICs (Pune and Jalna) are partially functional
<b>Meghalaya</b>	3 districts have operational DEICs (East Khasi, West Jaintia, West Garo)
<b>Tripura</b>	3 DEICs approved, though none are operational
<b>Uttar Pradesh</b>	No DEICs in the state; funds have been released for 2 (Aligarh, Moradabad)

Since there is no formal mechanism in-place for follow-up with parents by MHTs, this process is weak. Follow-up by MHTs is based on their own discretion, motivation, and level of engagement with the programme. Follow-up tends to be weaker for developmental delays and health conditions that do not have a designated treatment protocol. Often, it was observed that MHTs do not report children with developmental delays as there is no clear or shorter treatment available for them.

### Perception of, focus of senior policy makers on the programme

The perception of the importance of RBSK among health functionaries and focus on the programme itself was found to be weak. Interactions with NHM Mission Directors in the study states demonstrated that their own knowledge of the programme was limited, and they did not advocate for its importance or implementation with other officials. Under the child health umbrella, there appears to be greater focus on initiatives such as Routine Immunisation rather than programmes like RBSK. This was also demonstrated by the frequency with which MHTs were being utilised for other programmes, such as deworming and WIFS, instead of focusing on RBSK screening.

### Community mobilisation

The role of community members, including ASHAs, ANMs, AWWs, and school teachers, play a key role in ensuring smooth implementation of the programme. However, their level of involvement varies greatly. It is covered in detail in this Chapter subsequently under the section on Frontline Workers.

### RBSK Branding and IEC efforts

The Government of India had a soft launch for RBSK, with hardly any community mobilization activities or IEC/BCC materials disseminated for wider outreach of the programme. While the MoHFW with UNICEF support has developed a few pamphlets/posters for branding of RBSK vehicles, very few district had IEC materials available with them for RBSK. Some states had received materials, but this has neither been distributed nor put-up for display on vehicles. The greater challenge in usage of IEC materials is that since MHT vehicles are contracted out rather than owned, stickers or other materials cannot be used to brand the vehicles.

In addition, none of the schools, AWCs, or public health facilities visited had any posters/wall paintings/pamphlets/display boards for improving awareness on the programme, and its benefits. The only source of outreach appears to be in the form of community mobilization activities conducted by AWWs, and school teachers when the MHTs are expected to come for screening.

### Poor focus on IEC/BCC

There is overall a poor focus on IEC/ BCC for the programme. This is exacerbated by a weak understanding among health officials of the importance of IEC/ BCC and its potential for impact in improving programme understanding and uptake among beneficiaries.

In addition, of the total budget approved for IEC/ BCC activities, the five states have allocated varying amounts on RBSK-related IEC/ BCC activities. Further, the IEC/ BCC activities is being limited to printing registers and cards. The expenditure details were not available, hence the approved funding for the five states is summarized below.

**Table 11: IEC/ BCC allocation for RBSK**

Spend Categories (INR Lakhs)	Maharashtra	Karnataka	UP	Meghalaya	Tripura
<b>Amount approved for IEC/ BCC</b>	1294.2	603.66	8404.32	235.91	57.72
<b>IEC/ BCC approved under RBSK</b>	465.22	0	876.83	29.14	25.96
<i>Printing of RBSK card and Registers</i>	463.62	0	876.83	26.14	25.96
<i>Printing cost for DEIC</i>	1.6	0	0	3	0

### Training under RBSK

Training is an important step in ensuring that the related human resources are oriented and can deliver the programme as envisioned in the guidelines. Limited focus on the programme is further demonstrated by the slow progress made in RBSK training. The table below illustrates the training budget and expenditure for RBSK for the five states.

**Table 12: RBSK training (2014-15)**

(INR Lakhs)	Maharashtra	Karnataka	UP	Meghalaya	Tripura
<b>RBSK training – budgeted</b>	133.7	59	0	0	28.7
<b>RBSK training – actual expenditure</b>	74.1	0	44.7	3.7	0.1
<b>Training budget utilisation</b>	<b>55%</b>	<b>0%</b>	-	-	<b>0%</b>

As shown in the table, focus and thus expenditure on RBSK training has been minimal. Financial utilization for RBSK training is over 50% for only one of the five study states (Maharashtra), whereas no or minimal expenditure on RBSK training has been incurred in Karnataka and Tripura. In Uttar Pradesh and Meghalaya, however, no budget has been provided for RBSK training, while expenditure has been incurred. This poor focus on the programme has led to slow programme implementation, for example in the form of screening by ASHAs at home and MOs in delivery points yet to pick up, and slow progress on operationalisation of DEICs. This, in turn, affects successful delivery of the programme, and creates a reluctance among beneficiaries to use its services.

### Training Needs of Different Functionaries

Further, based on interactions with different officials across State, District and Block, diverse training gaps have been identified, as indicated below:

Level	Training related gaps
State Health Officials	<ul style="list-style-type: none"> <li>• Sensitization on the details of RBSK and its potential role in minimizing future disabilities in India</li> <li>• Capacity to create MoUs for appropriate partnerships with private sector, non-profit organization and civil society organizations who can assist with funding tertiary care for BPL families</li> <li>• Training to map key service providers offering tertiary care and management services across their state</li> <li>• Understand RBSK related IEC/BCC requirements and ability to support development of content for state specific IEC/BCC materials</li> </ul>
District Health Officials	<ul style="list-style-type: none"> <li>• Sensitization on the details of RBSK and its role in minimizing future disabilities in India</li> <li>• Capacity to train MHTs and FLWs on RBSK for improved service delivery</li> <li>• Understand importance of IEC/BCC activities</li> </ul>
Block Health Officials	<ul style="list-style-type: none"> <li>• Sensitization on the details of RBSK and its potential role in minimizing future disabilities in India</li> <li>• Capacity to train MHTs and FLWs on RBSK for improved service delivery</li> <li>• Understand importance of IEC/BCC activities</li> </ul>
Service Providers (Medical Officers) across DHs/CHCs/PHCs	<ul style="list-style-type: none"> <li>• Sensitization on the details of RBSK and its potential role in minimizing future disabilities in India</li> <li>• Guide patients on next steps or higher facilities to be visited</li> </ul>
IEC Officials	<ul style="list-style-type: none"> <li>• Ability to customise and contextualise communications approaches for state specific IEC/BCC activities based on the National Communication Framework for RBSK</li> <li>• IEC Officials are required to train District level IEC officials on using and disseminating IEC/BCC materials</li> </ul>
Other Departments	<ul style="list-style-type: none"> <li>• Sensitization about RBSK and understanding its objectives</li> <li>• Understanding of the role of convergence mechanisms for success of RBSK and how to operationalise convergence</li> </ul>
Mobile Health Teams	<ul style="list-style-type: none"> <li>• Annual refresher training for MHTs</li> <li>• Soft skills for IPC and counselling of caregivers</li> </ul>
Frontline Workers/Teachers	<ul style="list-style-type: none"> <li>• Sensitization about RBSK and understanding of its objectives</li> <li>• Soft skills for IPC and counselling of caregivers for follow-up care</li> </ul>

## Good practices

States have introduced several good practices to improve RBSK implementation and service delivery. Key among these are discussed below.

### Use of WhatsApp groups

WhatsApp groups were being used by MHTs of all the states visited during the study. These groups were being used to share knowledge on a larger platform, predominantly to exchange information on service providers and health conditions. The groups were particularly handy for cases that were more challenging and complex, and when MHTs did not know what was to be done. In such cases, WhatsApp groups were valuable in reaching out to a larger audience to get second and third opinions.

### Complementary state health insurance schemes

All study states except UP had health insurance schemes in place that were complementary to RBSK as they covered several conditions also covered under RBSK. These insurance schemes, with a range of coverage amounts, conditions, and eligible groups, were immensely helpful in alleviating the financial burden for caregivers. Such schemes include:

- Maharashtra: Rajiv Gandhi Jeevandayee Arogya Yojana, which covers 37 RBSK surgeries for both BPL and APL children
- Karnataka: Suvarna Arogya Chaitanya Programme for school going children, Yeshasvini for farmers, Vajpayee Arogyasri for BPL, which also provides TA/DA and is affiliated with hospitals in other states
- Meghalaya: Megha Health Insurance Scheme, which uses the existing RSBY framework to cover all residents of the state
- Tripura: Tripura Health Assurance Scheme for Poor, which provides health insurance to BPL families

### Providing transport to health facilities

In Uttar Pradesh, MHTs do not conduct screening once a week (typically Saturdays), and instead are stationed at a CHC to support families availing referrals under RBSK. They help in transporting families to DHs to avail treatment. This is hugely beneficial for those families that are unable to afford or arrange their own transport to a facility, and might not otherwise have accessed care.

Similarly, in Tripura, MHTs are involved in transporting and accompanying group of families to Agartala for treatment. This, in addition to helping families overcome the transport barrier, is also useful as the presence of an MHT staff helps families with navigating processes in a large city and in the health facility. As going to city such as Agartala can be overwhelming and challenging for families used to living in villages, being accompanied by MHTs provides a source of comfort and familiarity for them as well.

### Camp-based approach

In Tripura, a camp-based approach is used for RBSK treatment. This is mainly in response to the shortage of medical personnel in the state. As a result, medical specialists are brought to Agartala, and children that have been screened to have a condition under RBSK are brought to these camps to avail treatment.

Camps are also organized in Maharashtra, but predominantly for evaluation. Through tie-ups with private pediatric surgeons, bi-monthly camps are organized to evaluate children with birth defects requiring surgical procedures. These camps receive support from Pediatric Surgeons Association of India.

### Other state-specific good practices

- In Maharashtra, a web-based tracking platform that was developed by TCS for the state insurance scheme is being expanded to also track children screened under RBSK.
- In Barabanki, Uttar Pradesh, since no formal training for RBSK has been initiated for teachers, the Health and Education Departments have proposed a short session by a PHC doctor on RBSK as part of a 3-5 day teacher training, to sensitise teachers on the programme.
- In Meghalaya, BDS doctors (i.e., dentists) have been used to staff MHTs instead of AYUSH, in certain districts where AYUSH doctors are in short supply and BDS doctors are easily available. Similarly, some teams are also staffed with two female doctors instead of one male and one female. Such state specific nuances and cultural differences can be taken into consideration while outlining guidelines for MHT composition, as each state might not have adequate availability of each type of medical personnel as specified in the current guidelines.

The next section covers Knowledge, Attitudes, Beliefs, and Practices from focus group discussions with Mobile Health Teams and Frontline Workers.

## Mobile Health Teams

### Profile and role

Mobile Health Teams are the dedicated screening team of RBSK who conduct screening at both AWCs and schools. Typically, each block has up to 3 Mobile Health Teams depending on the size of the block and the population. Most of the MHTs in the focus group discussions were mixed group composed of Medical Officers (MOs), Lady Medical Officers (LMOs), Pharmacists, Staff Nurses / ANMs.

They play a pivotal role in being the link between the communities, caregivers and the health system. Generally, the knowledge of RBSK among community members was limited to the visits made by these RBSK Mobile Health Teams. It was observed that the success of the programme, especially in terms of follow-up and treatment, hinged on the motivation and pro-activeness of these teams.

### Key findings from primary interactions

#### Knowledge

*Since the MHTs are the backbone of the programme, their knowledge of the programme, clarity of their roles in the programme, awareness of ways to prevent birth defects and developmental delays was ascertained. Awareness of community members regarding RBSK was also enquired*

All the respondents were aware of RBSK, and its details about the conditions covered and the continuum of care offered under RBSK. They were able to list the conditions covered under the programme and were able to explain the process involved in the programme. A few of the respondents even stressed on the fact that this programme is universal, and that it covers all children in the age group 0-18 years, regardless of their poverty status, caste, religion, gender, and disability status. They recognized the role of the programme in minimizing disabilities through early intervention.

Apart from listing screening as their primary role, many respondents also mentioned dispensing medicines such as IFA tablets, vitamin supplements as part of their role in the programme. They also stated their involvement in preparation of micro-plans, coordination with Anganwadi Workers and teachers prior to screening, and maintenance of registers/screening cards.

However, some respondent perceived 'training adolescent girls on how to use sanitary napkins, handwashing hygiene to school children, proper nutrition and diet, counselling children on sanitation', as part of their role in the programme.

In addition, most RBSK MHT members felt that many community members and parents were not aware of RBSK since they had not received any direct communication from MHTs or via other IEC activities. However, they also felt that while parents and communities may not be aware of the details of RBSK, they would know of a team of doctors coming to Anganwadis and schools for check-up. This is further validated by findings from caregivers; nearly 55% of the caregivers are aware of the 'team of doctors coming to anganwadis and schools', however, are unaware of the details. They added that only parents whose children were screened with a 2D were aware of the programme due to their experience with the referral and evaluation system.

#### Attitude

All MHT members had a very supportive attitude towards children with 2Ds, and strongly felt the need to support these families by empowering them with knowledge about the condition and next steps in the form of evaluation and treatment. All respondents unequivocally felt that children with 2Ds require more

attention and care from parents, and communities. They felt that a programme such as RBSK is beneficial as it serves the needs of the low-income families with children with 2Ds.

### Beliefs

Many of the respondents attributed the causes of these conditions to consanguineous marriage, maternal age, poor nutrition and lack of rest/care during pregnancy, poor ANC check-ups, lack of immunization, etc.

Most respondents believe that a programme like RBSK is extremely beneficial, as they realize its potential to avoid future complications for the child. In addition, many respondents felt that this programme is preventive in nature, in that, it screens for 2Ds, making the parents aware of anything that is potentially 'different' about their child's developmental milestones or birth defects that could be latent. All the respondents felt that this was extremely beneficial for low-income communities for two reasons; first, they might not have known of their children's condition otherwise. And second, even if they had known, they would never be able to afford surgeries, or expensive treatments without the provision of free treatment under RBSK.

*"There are some birth defects like club foot which when found at an early stage can prevent this from aggravating, else it could lead to disability in the child."*

- Medical Officer, MHT, Kalaburagi, Karnataka

*"Of course it is very important, many children are able to walk now, able to hear and speak now, just because of RBSK"*

- Lady Medical Officer, MHT, Aurangabad, Maharashtra

### Practices

*Since RBSK teams conduct screening, they were questioned about people's practices after screening, particularly with respect to follow-up for evaluation and management*

There is a lot of variation in terms of follow-up conducted by MHT members – a few teams follow-up personally, while a few of them conduct a weekly evaluation camp at the nearest PHCs where parents can bring their children. A few of them track parents who come to DEICs, and a few of the teams handed over the responsibility of follow-up to ASHAs, AWWs and teachers. Respondents felt that despite approaching parents or informing parents about the future course of action, parents face a multitude of barriers including, financial, transport, mistrust with the government health system, and, caretaking of other children in the household. All of these barriers were also echoed in the caregivers' interviews.

*"For the CHD cases, we have to refer the patient to Bangalore only because there is no DEIC in Kalaburagi so parents think about how they can travel 700 kms from here and manage all things"*

- Medical Officer, Kalaburagi, Karnataka

Further, despite initial setbacks in terms of convincing parents, they try to call up parents on their mobiles and explain the importance of screening and early intervention in ensuring a better future for their children. Further, for parents of female children with 2Ds, they try to convince them by highlighting the likely obstacles in getting them married. In a few cases, they involve AWWs and teachers to counsel parents.

All the respondents undeniably felt the need to have counselling skills embedded into their training modules. They felt that having booklets, preferably, pictorially with the defects and developmental delays, could help in explaining the conditions to uneducated/semi-literate parents.

## Frontline Workers

### Role

#### *Accredited Social Health Activists (ASHAs)*

ASHAs are women from the same community trained as health educators and social activists to bring about behaviour change. For RBSK, their role includes providing home based screening of new born in the 0-6 week category and community mobilization during screening visits by MHTs to Anganwadi Centers.

#### *Anganwadi Workers (AWWs)*

AWWs are also workers from the community who manage the Anganwadi Centre in their village. In the context of RBSK, their primary role is mobilisation of parents of children below the age of 6 years to their Centres when the MHTs conduct their screening visits.

#### *Auxiliary Nurse Midwife (ANM)*

ANMs are village-level health workers, present at each Sub-Centre, who serve as the first point of contact between the community and the primary healthcare system. Their role in the programme includes screening for any birth defects and developmental delays among newborns delivered at their Sub-Centre.

### Key findings from primary interactions

#### Knowledge

Most ASHAs are aware of basic programme details, such as the screening that takes place at schools and AWCs. However, most are unaware of larger programme details or objectives, and have not received any formal training. As a result of this lack of training, their knowledge of the 2Ds is limited to visible birth defects such as cleft lip and palate and club foot.

The knowledge of AWWs regarding the programme is similar to that of ASHAs; they are aware of the screening that takes place, but do not know of further programme details and have not received any formal training or sensitisation.

However, the knowledge of ANMs regarding the programme is also limited. However, they have an understanding of some of the 2Ds, such as cleft lip and palate, club foot, Down's syndrome, etc., as they have seen children with such ailments.

#### Attitude

Most frontline workers are supportive and sympathetic towards children with 2Ds. They support their parents, counselling and advising them to avail treatment for their children.

#### Beliefs

Beliefs of frontline workers about the causes of 2Ds do not relate to myths and superstitions. Instead, most respondents felt that 2Ds were due to genetic causes, consanguineous marriages, and poor antenatal care during pregnancy, etc. Regardless of the cause, most frontline workers feel that early intervention is essential, and can be extremely beneficial in curing the condition or minimising disability.

Further, most respondents felt, after learning more about the programme, that it is extremely beneficial, especially for poor families who would not otherwise be able to afford treatment. They did feel, however, that awareness of the programme is low, even among health workers. A critical step towards improving programme awareness and uptake is improving awareness among frontline workers, so that they can subsequently mobilise the community.

### Practices

ASHAs have a limited role in RBSK delivery, especially since home-based screening for newborns has not been rolled-out. As a result, in addition to not having received any training, they have also not received job aids or pictorial toolkits for RBSK. Typically, if ASHAs identify some of the more visible or obvious birth defects during their home-based newborn care, they inform the local ANM and suggest to the parents that they visit the nearest PHC or CHC. In some cases, ASHAs also counsel the parents and conduct regular follow-up visits. Their role in community mobilisation during RBSK visits, however, is voluntary and usually limited, and almost entirely dependent on their relationship with the AWW.

However, AWWs play a role in mobilising children for screening, after receiving intimation from MHTs about an impending visit. After screening, they often are also involved in counselling and following up with parents.

Further, the involvement of ANMs in the programme, and their interaction with MHTs, is limited. Their link with the programme is through ASHAs, who usually inform them about children with 4Ds. The role of ANMs is typically limited to referring such cases to PHCs/ CHCs/ DHs for further evaluation and treatment.

# Chapter 4b: Key Findings from Other Departments

## Key Takeaways:

The chapter includes both a comparison of the interventions introduced by the various relevant Departments for children with special needs as well as an analysis of how convergence between these Departments can be useful to improve RBSK service delivery.

### Interventions by other Departments

- **Inclusive Education (IE) programme** of Sarva Shiksha Abhiyan (SSA) by Ministry of Human Resources Development (MHRD)
- **District Disability Rehabilitation Centres (DDRCs)** by Ministry of Social Justice and Empowerment (MSJE)

Although, both the programmes make an attempt to identify children/persons with disabilities, RBSK is the only programme that aims to screen all children regularly for any defects at birth or developmental delays.

### Convergence with other Ministries and Departments is weak

- Currently there are no collaborations between RBSK and interventions by other ministries that also cater to disabled children
- There is an overlap of staff in DDRCs and DEICs to some extent, hence the potential of co-locating the two facilities could be considered
- Special education teachers employed by the IE programme could be leveraged to counsel parents of children screened to have a condition under RBSK

### Knowledge of RBSK and involvement of Other Department Officials

- Since no formal training or sensitization seems to have been provided to any of the related government Department officials, many district- and state-level education and ICDS, and Disability Welfare Department officials are unaware of RBSK
- Variance in the involvement of other departments in RBSK related activities e.g. development of micro-plans for RBSK

Since this programme is implemented through touch points and personnel that are under the purview of other Departments, it is important to understand the convergence mechanisms between Health and other Departments (including Women and Child Development, Human Resource Development, Social Justice and Empowerment). Given that these other Departments also implement some of their own schemes and programmes for children with special needs, there is a huge potential for synergies and overlap with RBSK.

The section below includes both a comparison of the interventions introduced by the various relevant Departments for children with special needs as well as an analysis of the convergence between these departments for RBSK implementation.

### Interventions by other Departments

There are programmes/interventions being implemented by other Ministries/Departments including Inclusive Education (IE) programme of Sarva Shiksha Abhiyan (SSA) by Ministry of Human Resources

Development (MHRD) and District Disability Rehabilitation Centres (DDRCs) by Ministry of Social Justice and Empowerment (MoSJE). The table below summarizes details of these programmes and RBSK.

**Table 13: Snapshot of RBSK, DDRC and IE-SSA programmes**

	<b>RBSK</b>	<b>District Disability Rehabilitation Centres (DDRC)</b>	<b>Inclusive Education (IE), Sarva Shiksha Abhiyan (SSA)</b>
<b>Ministry</b>	Ministry of Health and Family Welfare	Ministry of Social Justice and Empowerment	Ministry of Human Resource Development
<b>Year of launch</b>	2013	1985-1990	2002-2003
<b>Beneficiary age group</b>	0-18 years	All age groups	6-14 years
<b>Objective of the programme</b>	Early intervention in a child's life to minimize disability	Rehabilitation of persons identified with various disabilities	Survey for identification of CWSN (Children With Special Needs) and assessment of CSWN
<b>Programme details</b>	Identification and treatment of 4Ds (Defects, Delays, Diseases and Deficiencies), referral and free treatment of children through a regular screening process	Rehabilitation support for persons with disabilities	Under SSA, a continuum of educational options, learning aids and tools, mobility assistance, support services etc. are made available to students with disabilities. It also includes the appointment of resource teachers, networking with NGOs / Govt. Schemes, providing barrier-free access and curricular adaptation of textbooks / teaching-learning materials.
<b>Administrative structures at district</b>	Civil Surgeon, District RBSK Nodal Officer	Deputy Commissioner head, District Disability Rehabilitation Officer	SSA officer at District
<b>Front line workers involved in the programme</b>	AWWs, AWHs, ASHAs	Village Rehabilitation Worker (VRW at Gram Panchayat level, an honorarium-based worker who identifies persons with disabilities); Multi-purpose Rehabilitation	-

	<b>RBSK</b>	<b>District Disability Rehabilitation Centres (DDRC)</b>	<b>Inclusive Education (IE), Sarva Shiksha Abhiyan (SSA)</b>
		Worker (MRW) at Block Level.	
<b>Screening method</b>	By dedicated RBSK Block-level Mobile Health Teams in Schools and AWCs (Anganwadi Centres)	Camp-based approach	By a Medical Board (team of specialists) in the camps
<b>Frequency of screening</b>	AWC- Twice a year School- Once a year	No specified timeframe	Once a year
<b>Main facilities provided</b>	Early intervention and referral to DEICs (District Early Intervention Centre) and other health facilities	Rehabilitative support to persons with disabilities at DDRCs (District Disability Rehabilitation Centres)  Offers Braille books to visually impaired children	Set-up of disabled friendly infrastructure at government schools such as ramps, disabled-friendly toilets. Home-based education for severely disabled children through special instructors Also, offers Braille books to visually impaired children
<b>Aids and equipment provided</b>	Children provided rehabilitative and assistive devices, as required	Aids, equipment such as artificial limb, spectacles, etc. distributed through camps of various NGOs and ALIMCO.	Up to INR 3000 per child per year that covers cost of free equipment such as spectacles, crutches, artificial limb, etc.
<b>Financial support</b>	No particular pension/amount disbursed to the family	Monthly maintenance allowance of INR 1200, for persons with disabilities who have a Disability Certificate	No particular pension/amount disbursed to the family
<b>Key personnel</b>	Mobile Health Team and DEIC staff	DDRC staff	Special Education resource teachers
<b>Community mobilization</b>	Through AWWs, and school teachers	Through District / Zila and Taluk Panchayats	Through school teachers

### **SSA's IE Programme under MHRD**

The IE programme primarily cater to educational needs of children with special needs including home-based for severely disabled children through special education resource teacher, conducting an annual medical camp to identify children with potential disabilities, and provision of learning aids, braille books, and assistive devices such as spectacles, crutches, artificial limb, etc. It also aims to improve physical accessibility to government schools through provision of disabled friendly with ramps, and disabled friendly toilets. This programme only uses special education resources teachers for its implementation. The school teachers are not provided any form of pre-service or in-service training to cater to the requirements of children with special needs.

### **DDRC Programme under MoSJE**

Whereas, the programmes run by MoSJE cater to persons with disabilities (PWDs) with an objective of rehabilitating them. District Disability Rehabilitation Centre (DDRC)<sup>34</sup> Scheme was launched to provide comprehensive rehabilitation services to rural PWDs. The objectives of the DDRC include surveying the disabled population, prevention, early detection and medical intervention and surgical correction, fitting of artificial aids and appliances, therapeutic services– physiotherapy, occupational therapy and speech therapy, provision of educational services in special and integrated schools, provision of vocational training, job placement in local industries and trades, self-employment opportunities, awareness generation for the involvement of community and family to create a cadre of multi-disciplinary professionals to take care of major categories of disabled in the district.

It must be noted that although both the programmes make an attempt to identify children/persons with disabilities, RBSK is the only programme that aims to screen all children regularly for any defects at birth or developmental delays. Unlike the other two programmes (IE and DDRCs) that are more rehabilitative in nature, RBSK aims to be preventive, in that it aims to minimize disability.

### **Convergence Case Study with DDRC**

While there are potential synergies that could be explored in the future, currently there are no collaborations between RBSK and interventions by other ministries that also cater to disabled children. For example, the Ministry of Social Justice and Empowerment's DDRCs are staffed by several specialists that are in common with DEICs. The staff employed in the two facilities are provided below.

**Table 13: Staff employed in DEICs and DDRCs**

	DEIC	DDRC
<b>Paediatrician</b>	✓	✗
<b>Medical officer</b>	✓	✗
<b>Dentist</b>	✓	✗
<b>Physiotherapist/Occupational Therapist</b>	✓	✓
<b>Clinical/Rehabilitation Psychologist</b>	✓	✓

<sup>34</sup> Started in 1995

	DEIC	DDRC
<b>Orthopaedic Specialist</b>	✓	✓
<b>Audiologist/Speech Pathologist</b>	✓	✓
<b>Special Educator</b>	✓	✗
<b>ENT Specialist</b>	✓	✗
<b>Optometrist</b>	✓	✗
<b>Counsellor</b>	✓	✗
<b>Nutritionist</b>	✓	✗
<b>Neurologist</b>	✓	✗
<b>Psychiatrist</b>	✓	✗

### Poor convergence with related Ministries/Departments

Despite these overlaps, there are no referrals, linkages, or sharing of staff/ resources between DEICs and DDRCs in districts that have both, and no formal means of referral to DDRCs from RBSK in districts that do not have a DEIC. Given this overlap of staff, the potential of co-locating the two facilities could be considered.

In addition, the Inclusive Education Programme, too, has limited synergy with RBSK. Special education teachers employed by the programme could, for example, also be leveraged to counsel parents of children screened to have a condition under RBSK. However, no formal convergence between the two programmes has been set up so far.

### Knowledge of RBSK and involvement of Other Department Officials

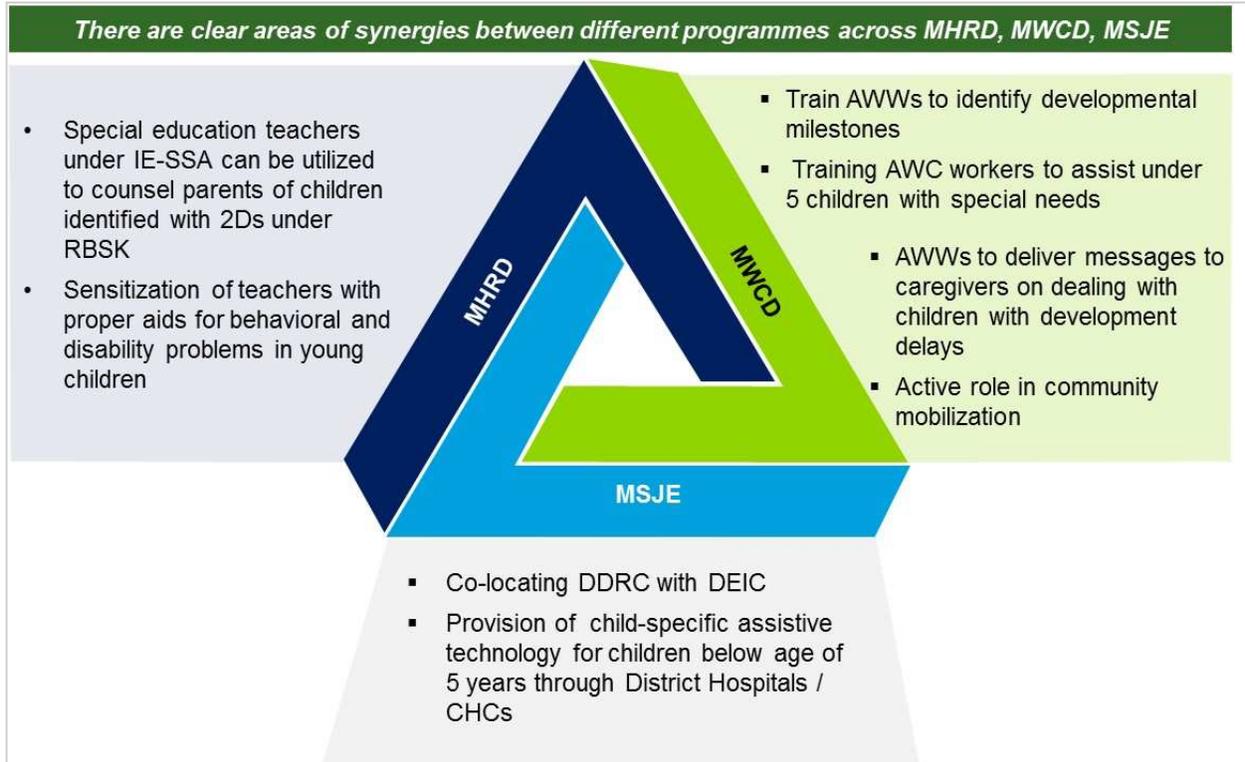
Many district- and state-level education and ICDS, and Disability Welfare department officials are unaware of RBSK itself. However, awareness was greater with the mention of 'School Health Programme', with officials often referring to RBSK as School Health Programme. Additionally, there was variance in the involvement of other departments in the development of micro plans for RBSK. In a few cases, BEOs and CDPOs were involved in drafting micro plans, or providing input. However, in most cases, they were simply given a copy of the plan. Beyond the block level, very little involvement in or even knowledge of micro plans seemed to exist.

Further, it was observed during the various interactions that, little or no formal training or sensitization seems to have been provided to any of the related government Department officials met in the five states. However, they were involved to the extent of attending convergence meetings wherever they took place, where typically RBSK was one of several agenda items discussed. These meetings were more common at the block and district levels, as compared to the state.

### Recommended Convergent Action

As indicated below, a convergent action between different Ministries of HRD, WCD and SJE is useful to improve service delivery under RBSK. Details of how to operationalise the convergent action is provided in the Report on Communication Framework.

**Exhibit 13: Recommended Convergent Action**





# Chapter 5: Policy Recommendations

## Key Takeaways:

The chapter includes policy and systemic recommendations to improve implementation and uptake of RBSK

### Policy Recommendations

- Focus on soft skills training and refresher trainings for MHTs
- Re-visiting daily screening targets for MHTs
- Provision of free diagnostics for the children screened to have 2Ds
- Enable transportation services for RBSK beneficiaries
- Dedicated helpdesks and kiosks for RBSK beneficiaries at public health facilities
- Empower AYUSH doctors as they are key liaison link workers for RBSK
- Strengthening network of tertiary care institutions including DEICs
- Addition of other common health conditions to state-specific implementation of RBSK
- Explore convergence mechanisms with other Departments and partnerships with NGOs and private sector

Based on supply-side findings, policy and systemic recommendations to improve programme implementation and uptake are summarised below.

## Policy Recommendations

### Provision of refresher trainings

There is a need to introduce training for different activities and audiences, to improve various facets of programme delivery. These training needs are summarized below, and already explained in detail in Chapter 4a.

- It is critical to have regular refresher trainings for MHTs, as one five day orientation training might not be sufficient. This need has also been expressed by several MHTs themselves
- It would also be useful to provide training for interpersonal communication and counselling skills for MHTs as they can be multi-skilled to educate and counsel caregivers
- From an IEC/ BCC perspective, there is a need to introduce training both to develop an understanding of the importance of IEC/ BCC activities for the programme among health functionaries (especially RBSK nodal officers), as well as for preparation of IEC/ BCC materials for State level RBSK staff
- Training and capacity building for advocacy is a big need among key state level officials. These officials must be equipped to advocate for key programmatic changes and improvements, as well as greater programme focus, and will be unable to do so without the appropriate training

### Re-visiting daily screening targets for MHTs

Daily targets have been found to be too ambitious, and the emphasis on targets is comprising the quality of the screening. These targets must thus be appropriately modified to ensure that proper screening is taking place. They must also take into account state nuances – for example, the terrain in states like Meghalaya and Tripura increases travel time for MHTs.

### Provision of free diagnostics

It is important to provide RBSK related diagnostics (e.g., 2D Echo) in a manner that ensures that caregivers do not have to bear the financial burden of expensive diagnostic procedures. This can be done in a number of ways: ensuring that operationalizing DEICs are expedited, making them available at DEICs, through tie-ups with private providers, or through NHM's Free Diagnostics Service Initiative.

### Enable transportation services for RBSK beneficiaries

Appropriate measures need to be taken to address the transport barrier for caregivers. Transportation facility once a month for a group of RBSK beneficiaries/caregivers may be explored.

### Dedicated helpdesks and kiosks for RBSK beneficiaries at public health facilities

Measures including setting-up of a dedicated RBSK kiosks/helpdesks at the referral facilities and holding special RBSK-specific evaluation on specific calendar dates (once a week) may be implemented to address navigation-related barriers at the facility-level.

### Empower AYUSH doctors as they are key liaison link workers for RBSK

Measures should be taken to further empower AYUSH doctors as they are a key liaison link worker for RBSK:

- MHTs are playing a crucial role and are often the link between the community and RBSK system of care. However, most MHTs are themselves not clear on their role in the programme. Interactions with AYUSH doctors revealed that they felt 'inadequate' since they do not 'treat' children, and do not provide medicines beyond IFA tablets or flu, diarrhoea medicines'. Many of the MHTs complained that they did not know where to send children with developmental delays. This was seen as a major service delivery challenge in the absence of DEICs.
- Also, their role in the programme is limited to screening and referring children screened to have 2Ds to PHCs/CHCs/DH. In the absence of follow-up assigned to MHTs, the sequence of action taken by the families, in terms of whether treatment was provided or not, is not communicated to the respective MHTs. This is a huge bottleneck, further fuelling communities' mistrust with the health system, i.e., MHTs. When MHTs return to the respective schools/ AWCs for screening, they feel the backlash from communities.
- The philosophy of RBSK should be made clear to the AYUSH doctors. The better-performing MHTs could be given a recognition '*badge*' to improve their motivation. Avenues for promotion for better-performing and seasoned AYUSH doctors could be created, through Central Government Health Services (CGHS) AYUSH dispensaries or as DEIC managers. Further, AYUSH doctors could use a monthly VHND platform to educate caregivers about the importance of follow-up after screening.
- A provision for smartphone-based application or a database with an electronic record of all children can be made for tracking each child screened. MHTs could be made accountable for tracking children. This could enhance their motivation in the programme and create a sense of purpose beyond screening.
- MHTs doctors could be multi-skilled to provide counselling services to parents, especially on how to cope with children with developmental delays. These could be once in two years training program with skills training imparted to AYUSH doctors. Connecting all MHTs in a district through WhatsApp to discuss innovations and to seek funding for treatments or find service providers for children with developmental delays or special needs could be encouraged.

### Strengthening network of tertiary care institutions including DEICs

There is a huge need to strengthen the tertiary-level referral network for RBSK. This is a three-fold need:

- A greater number of DEICs need to be operationalized, so that caregivers are able to avail all services under a single umbrella instead of being sent from one facility to another. Here, too, advocacy training for state level officials will be key in facilitating a push for DEICs
- Facility mapping of available health facilities is necessary, to understand current availability of diagnostic, rehabilitative and curative health services; this information must be made available at all public health facilities and with MHTs to educate the caregivers of children with 2Ds
- In the absence of sufficient DEICs, MoUs or referral agreements must be entered into with other health facilities, including private facilities, health facilities in other neighbouring states where children are being referred, and missionary hospitals (especially in states such as Meghalaya and Tripura that have a large Christian population)

### Addition of other common health conditions to state-specific implementation of RBSK

A few conditions including Imperforate anus, squint are not under the 30 conditions listed under RBSK. However, States are encouraged to added common conditions relevant for children aged 0-18 years under RBSK to ensure it is comprehensive and addresses all the possible health conditions. Accordingly, the MHT trainings for each state will also cover these extra health conditions.

### Explore convergence mechanisms with other Departments and partnerships with NGOs and private sector

Stronger convergence mechanisms are required between Health and other related Departments (including Women and Child Development, Human Resource Development, Social Justice and Empowerment). This must be done in the form of regular meetings with the appropriate officials at the state, district, and block levels and provision of formal training or sensitization on RBSK to officials of other Departments and their frontline workers or field representatives (AWWs and teachers). Additionally, scope for synergies or linkages between RBSK and other similar programmes or initiatives by other Departments (such as SSA's Inclusive Education, Social Justice and Empowerment's District Disability Rehabilitation Centres) can be looked into.

Although the study did not cover representatives from non-profits, civil society organizations and private sector, it came up during several interactions. District-level officials could attempt to map services resources made available by these organizations for caregivers and their children with special needs. Use of NGOs, CSOs could be explored for outreach and community awareness activities as well. For instance, Vidyasagar, a non-profit in Chennai for children with multiple disabilities has an ongoing partnership with local hospitals and assessment centres to which it refers its clients. Vidyasagar provides family-based rehabilitation by demystifying disabilities empowering and training the parent /family/caregiver to effectively meet the special needs of their child. Similarly, Genesis Foundation, a non-profit in Gurgaon provides financial assistance to ill underprivileged children who require heart surgeries and other medical interventions.

# Annex 1: Database of Stakeholders Met

## Database of stakeholders met in Maharashtra

Administrative Level	Location	Designation	Name
District	Aurangabad	MO, MHT	Dr. Santosh Rathod
District	Aurangabad	District Program Assistant	Mr. Kailas Tatikondalwar
District	Aurangabad	RMO, Civil Hospital and RBSK nodal officer	Dr. V. S Bhatgar
District	Aurangabad	CS, Civil Hospital	Dr. G. M Gaikwad
District	Aurangabad	ICDS Officer	Dr. Sanjay Kadam
District	Aurangabad	NRHM Coordinator	Ms. Sampada Chavan
District	Aurangabad	SSA Coordinator	Mr. V. R Wakude
District	Aurangabad	DEO- Primary	Mr. M. K Deshmukh
Block	Khultabad	MS, Rural Hospital	Dr. Santosh B Naikwad
Block	Khultabad	CDPO	Mr. Thorat
Block	Khultabad	SSA Coordinator	Mr. Rakesh Appa Sahib Khairnar
Block	Khultabad	MO, MHT	Dr. Bhavdeep Kale
Block	Khultabad	MO, MHT	Dr. Amol Chavan
Block	Khultabad	MO, MHT and RBSK coordinator	Dr. Swati Puranik
Block	Sillod	MS, SDH	
Block	Sillod	CDPO	Mr. N.K Dunkalwar
Block	Sillod	SSA team (Coordinator+worker)	Mr. Sonkamle and Mr. Rajkumar
Block	Sillod	Medical Officer- MHT	Dr. Sanjay Magar
Block	Sillod	Medical Officer- MHT	Dr. Ram Burkul
Block	Sillod	Medical Officer- MHT	Dr. Jayshree Pawar
Block	Sillod	Medical Officer- MHT	Dr. Bhagti Pawar
Block	Sillod	ANM	Ms. Sangita Jadhav

### Database of stakeholders met in Karnataka

Administrative Level	Location	Designation	Name
District	Raichur	RCHO	Dr. Vijaya.K
Block	DevDurga	MO, MHT	Dr Riyaz.S
Block	DevDurga	Ophthalmic Assistant, MHT	Mr. Vijay
Block	DevDurga	Staff Nurse, MHT	Ms. Manjula.B
Block	DevDurga	ASHA Worker	Mr. Usan.B
Block	DevDurga	Head Teacher	Ms. Saumangala
Block	DevDurga	School Teacher	Ms. Sherila
Block	DevDurga	Block Official	Mr. Chandrakant
Block	DevDurga	MO, MHT	Dr Abhilekha
Block	Sindhanaur	MO, MHT	Dr Ajjan genda
Block	Sindhanaur	MO, MHT	Dr Ambuj
Block	Sindhanaur	Ophthalmic Assistant, MHT	Mr. A. Basauaraj
Block	Sindhanaur	Head Teacher	Mr. Shiv Kumar.S
District	Sindhanaur	School Teacher	Mr. Srinivas
Block	Sindhanaur	ANM	Mr. Hanumantamma
Block	Sindhanaur	ASHA Worker	Ms. Lakshmi
District	Raichur	Head Teacher	S. Baburao
District	Raichur	SSA official	Ms. Vasalingama
District	Raichur	DHO	Dr. Narayanappa
District	Raichur	Education Officer	Ms. Indira
District	Raichur	Deputy Director, WCD	Mr. Ashok Kelwadi
Block	Sindhanaur	CDPO	Ms. Yogita
District	Raichur	District Disabled Welfare Officer	Mr. Sharanappa

## Database of stakeholders met in Meghalaya

Administrative Level	Meeting Location	Designation	Name
State	Shillong	Joint Director Health Services(MCH and FW)	Dr. (Mrs.) B. Mawthoh
State	Shillong	State RBSK Coordinator	Mr. A.S. Augustinc
District	Shillong	DEIC Manager, East Khasi Hills	Mr. Johnson J. Nongbet
State	Shillong	UNICEF RMNCH Consultant	Mr. Rakesh Singh
District	Shillong	M & H.O, DEIC East Khasi Hills	Dr. (Mrs.) E. M Dhar
State	Shillong	DHS(MCH and FW)	Dr. Wanpli kharkrang
District	Nongstein, West Khasi Hills	ICDS officer	Mrs. Matti Wanniang
District	Nongstein, West Khasi Hills	SDSEO(Sub Division School Education Officer)	Mr. E. Marngon
District	Nongstein, West Khasi Hills	Sub Inspector of School	Mr. R. G. Mormin
District	Nongstein, West Khasi Hills	DMHO	Dr. W.W. Phira
Block	Mairang, West Khasi Hills	CDPO	Ms. Eva Slong
Block	Mairang, West Khasi Hills	BMC-SSA(Block Mission Coordinator)	Mr. F. Marwein
Block	Mairang, West Khasi Hills	Vice Principal	Dinoris Lyngdoh Mawlich
District	DEIC, East Khasi Hills	Dentist	Dr. Alice Lyngdoh
District	DEIC, East Khasi Hills	Staff Nurse	S/N Margaret Bamon
District	DEIC, East Khasi Hills	Staff Nurse	S/N Shanti Rajee
District	DEIC, East Khasi Hills	Physiotherapist	Ms. Emily Jones Malngiang
District	DEIC, East Khasi Hills	Ophthalmic Assistant	Ms. Kerry Zerene Pale
District	DEIC, East Khasi Hills	Laboratory Technician	Ms. Pynhunlin War
District	DEIC, East Khasi Hills	Social Worker	Ms. Euniky B. Lyngdoh
District	DEIC, East Khasi Hills	Psychologist	Ms. Lisette B. Swer
District	DEIC, East Khasi Hills	Data Entry Operator	Ms. Alyona L Nongkynrih
District	DEIC, East Khasi Hills	Audiologist and Speech Therapist	Ms. Eusebia B. Susngi
District	DEIC, East Khasi Hills	Educator	Ms. Doreen Thabah
Block	Mawthadraishan	MO, MHT	Dr. Ibanylla Malngiang
Block	Mawthadraishan	MO, MHT	Dr. Filldaris Khongiong
Block	Mawthadraishan	Staff Nurse, MHT	Ms. Tipsngi. Marngar
Block	Mawthadraishan	Lab technician, MHT	Ms. Peacefulness Dkhar
Block	Mawthadraishan	ANM, MHT	Ms. Darisha kharmawlong
Block	Mawthadraishan	MO, MHT	Dr. Siranjivi Harbaniang
Block	Mawthadraishan	MO, MHT	Dr. Barilang Bamon
Block	Mawthadraishan	Staff Nurse, MHT	Ms. Edmund Jyrwa

Administrative Level	Meeting Location	Designation	Name
Block	Mairang	MO, MHT	Dr. Pala
Block	Mairang	MO, MHT	Dr. Candy
Block	Mairang	Pharmacist, MHT	Ms. Fenitive
Block	Mairang	ANM, MHT	Ms. Dalante
Block	Mairang	Lab technician, MHT	Mr. Judith
Block	Mairang	MO, MHT	Dr. Leuy
Block	Mairang	MO, MHT	Dr. Jeremy
Block	Mairang	ANM, MHT	Ms. Shialy
Block	Mairang	RBSK Coordinator	Mr. Willbertstone Marngar
Block	Mairang	Social Welfare - Programme Officer	Ms. Hazzel
State	Shillong	Social Welfare Department Official	Ms. BB Nari
State	Shillong	Assistant Director, Social Welfare	Ms. LM Mumen
District	Nongstoin, West Khasi Hills	RBSK Nodal Officer	Dr. Laloo
State	Shillong	MO, DSEL	Mr. W. Nengnong
State	Shillong	Health, food and Nutrition consultant	Dr. Baphiralang
State	Shillong	MIS officer	Ms. Ouidio L. Kuskah

## Database of stakeholders met in Tripura

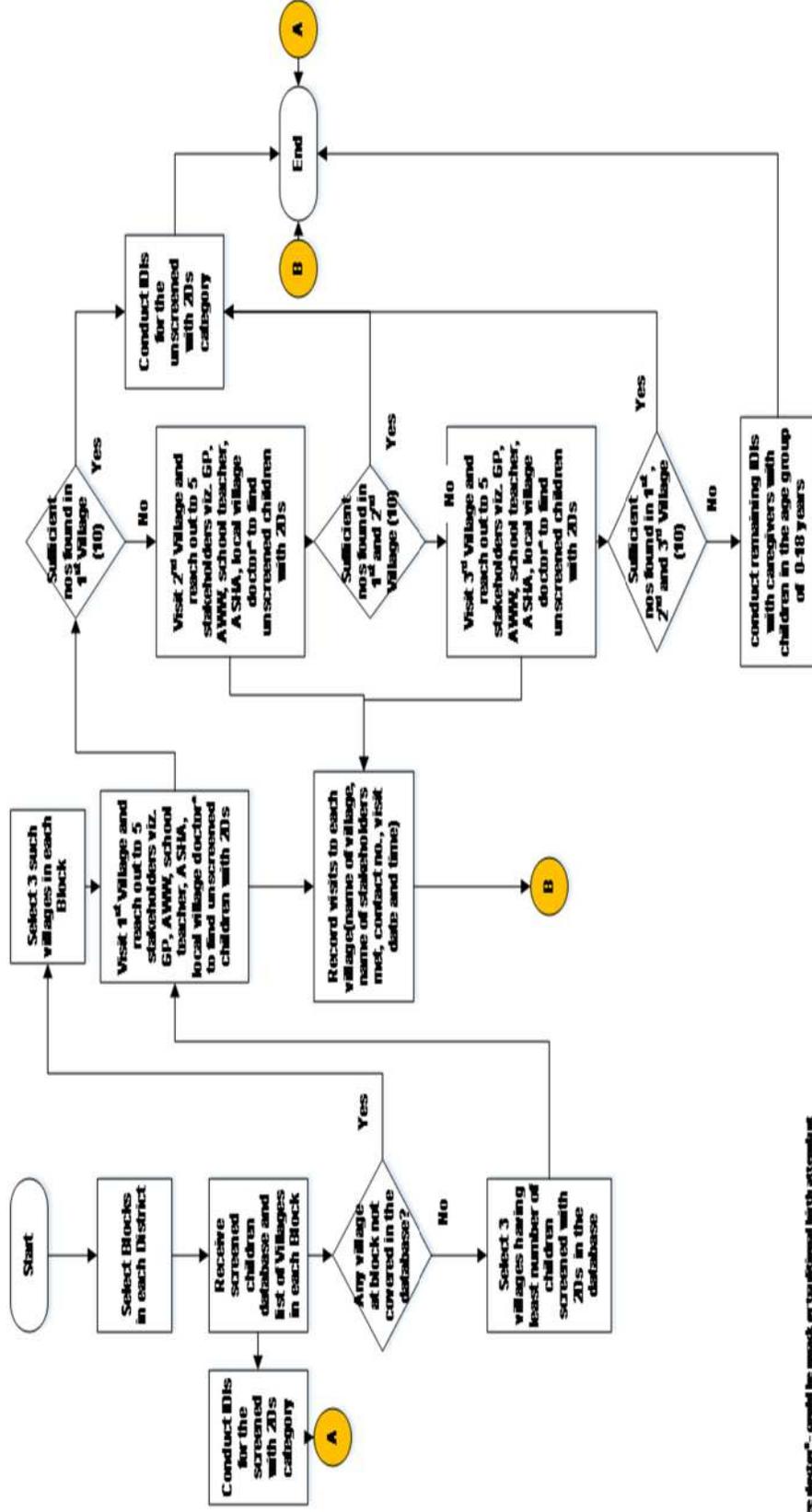
Administrative Level	Location	Designation	Name
State	Agartala	Nodal Officer, RBSK, NHM Tripura	Dr. B.K Sen
State	Agartala	Health Secretary	Mr. M. Nagarjun
State	Agartala	CAC, NHM, Tripura	Mr. Mridul Debroy
State	Agartala	Joint Director, Department of Education & Joint SPD, SSA, Tripura	Mr. Kuntal Das
State	Agartala	Joint Director, Secondary Education	Ms. Jogmaya Chakma
State	Agartala	Deputy Commissioner, SW&SE	Ms. Achitam Kilikla
State	Agartala	Consultant-RBSK, NHM, Tripura	Mr. Amit kr.Deb
State	Agartala	State RMNCH A Coordinator, UNICEF	Mr. Deepak kumar Biswal
State	Agartala	SSA State Coordinator	Ms. Susmita Sen
State	Agartala	CCM, NE-RRC	Dr.Supratim Biswas
State	Agartala	SF, NE-RRC	Mr. Arindam Saha
Block	Ambassa(Dhalai)	IS, Department of Education, TTADC	Krishnakanta Debbarma
District	Ambassa(Dhalai)	OSD, Department of Education (School)	Mr. Abamindra Pal
Block	Ambassa(Dhalai)	CDPO, Salema and Ambassa	Mr. Santosh Das
District	Ambassa(Dhalai)	District Inspector of Social Education	Mr. Uttam Acharya
District	Ambassa(Dhalai)	DMO,.CMO, Dhalai	Dr.Apdlo Kalai
District	Ambassa(Dhalai)	M.O, MHT	Dr. Arnab Deb Roy
District	Ambassa(Dhalai)	M.O, MHT	Dr. Mishti Deb
District	Ambassa(Dhalai)	M.O, MHT	Dr. Animesh Karmakar
District	Ambassa(Dhalai)	IED Coordinator(Education)	Mr. Suvankar Debnath
District	Ambassa(Dhalai)	APM, DHFWS, Dhalai	Ms. Sushma Rani Das
District	Ambassa(Dhalai)	Chief Medical officer(CMO)	Dr. Himadri Daring
District	Ambassa(Dhalai)	Pharmacist, MHT	Mr. Alok Bishwas
Block	Ambassa(Dhalai)	Head Teacher	Mr. Siburanjan Das

## Database of stakeholders met- UP

Administrative Level	Location	Designation	Name
District	Barabanki	Additional Chief Medical officer	Dr. Jeeta Singh
District	Barabanki	Nodal Officer	Mr. Dinesh Kumar Srivastava
Block	Fatehpur	Medical Officer	Dr. RC verma
Block	Fatehpur	ICDS officer	Mr. Shiv Saran Shiney
Block	Fatehpur	Block education officer	Mr. Shiv Singh
Block	Fatehpur	Block education officer - Coordinator	Mr. Dinesh Kumar Maurya
Block	Fatehpur	Block Health Officer	Ms. Shalini Chaudhary
Block	Fatehpur	MO, MHT	Dr. Sudhir Kumar
Block	Fatehpur	MO, MHT	Dr. Archana Verma
Block	Fatehpur	MO, MHT	Dr. Priyanka Choudhary
Block	Fatehpur	Ophthalmic Assistant, MHT	Mr. Deepak Chandra
Block	Fatehpur	Staff Nurse, MHT	Ms. Neshu Verma
Block	Fatehpur	Staff Nurse, MHT	Ms. Arti Verma
Block	Fatehpur	Ophthalmic Assistant, MHT	Mr. Akhilesh Verma
District	Barabanki	CMO	Mr. Ravindra Kumar
District	Barabanki	DPM	Mr. Amresh Dwivedi
District	Barabanki	RBSK MO	Dr. Malik Mohammad Salman
District	Barabanki	Optometrist	Ms. Savita Devi
District	Barabanki	Staff Nurse	Ms. Mitlesh
Block	Deva	Block Health Education Officer	Mr. Abhay Kumar
Block	Deva	RBSK MO	Dr. Prabha Chauhan
Block	Deva	RBSK GNM	Ms. Pratima Tiwari
Block	Deva	RBSK GNM	Ms. Prabha Pandey
Block	Deva	RBSK Optometrist	Mr. Bismillah
District	Barabanki	DPO, ICDS	Ms. Sharda Yadav
District	Barabanki	Basic Education Officer	Mr. Pratap Narain Singh
Block	Deva	CDPO	Ms. Reshma Hussain
Block	Deva	BEO	Mr. Rajendra Singh
State	Lucknow	SPO	Dr. Swapna Das
State	Lucknow	RBSK Consultant	Dr. Uttam Kumar
State	Lucknow	GM, RBSK	Dr. Hari Om Dikshit
State	Lucknow	Project Manager, ICDS	Ms. Aruthi Yadav
State	Lucknow	Upper Program Director, SSA	Mr. Ramesh Sharma
State	Lucknow	Sr. Professional (looks at IEP), SSA	Ms. Kamlesh Priyadarshini
Block	Deva	Head teacher	Ms. Seema Rai
Block	Deva	Caregiver	Ms. Rekha Devi

Administrative Level	Location	Designation	Name
Block	Deva	Caregiver	Ms. Sunita
District	Etah	RBSK Nodal Officer	Dr. S.S Pandey
District	Etah	District Community Mobilizer(ASHA)	Dr. Zubair Khan
District	Etah	District Program Manager(DPM)	Md. Arif
District	Etah	ICDS	Ms. Veena Solanki
District	Etah	Basic Education Officer	Mr. Shokeen Singh Yadav
Block	Awagarh	MO In charge, Block	Dr. Awadesh Kumar
Block	Awagarh	Block Education Officer	Mr. Mahesh Chand Patel
Block	Awagarh	Block Community Mobilizer	Mr. Ashok
Block	Awagarh	CDPO	Ms. Chitra Verma
Block	Awagarh	Head Teacher	Ms. Reena Singh

# Annex 2: Protocol to locate unscreened children



Village database - could be spread on the different health act cards