



National Communication Framework for RBSK

‘From Survival to Healthy Survival’

July 2016

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List of Abbreviations Used

2Ds	Birth Defects and Developmental Delays
4Ds	Birth Defects, Developmental Delays, Deficiencies and Diseases
ANC	Ante-Natal Care
ASHA	Accredited Social Health Activist
AV	Audio-Visual
AWC	Anganwadi Centre
AWW	Anganwadi Worker
AYUSH	Ayurveda, Yoga and Naturopathy, Unani, Siddha and Homoeopathy
BCC	Behaviour Change Communication
BPL	Below Poverty Line
C4D	Communication For Development
CD	Compact Disc
CHC	Community Health Centre
CHD	Congenital Heart Disease
CMO	Chief Medical Officer
CRC	Convention of the Rights of the Child
CS	Chief Surgeon
CSO	Civil Society Organizations
CWSN	Child With Special Needs
DC	District Commissioner
DDRC	District Disability Rehabilitation Centres
DEIC	District Early Intervention Centres
DEO	District Education Officer
DH	District Hospital
DHO	District Health Officer
DM	District Magistrate
FLW	Front Line Worker
FMR	Financial Management Report

GP	Gram Panchayat
ICDS	Integrated Child Development Services
ICT	Information and Communication Technology
IE	Inclusive Education
IEC	Information, Education and Communication
IFA	Iron and Folic Acid
IP	Informal healthcare Providers
IPC	Inter-Personal Communication
IVR	Interactive Voice Response
LMO	Lady Medical Officer
MDG	Millennium Development Goal
MHRD	Ministry of Human Resource Development
MHT	Mobile Health Team
MLA	Member of Legislative Assembly
MO	Medical Officer
MOD	March of Dimes
MoHFW	Ministry of Health and Family Welfare
MoU	Memorandum of Understanding
MP	Member of Parliament
MSJE	Ministry of Social Justice and Empowerment
MWCD	Ministry of Women and Child Development
NGO	Non-Governmental Organization
NHM	National Health Mission
PHC	Primary Health Centre
PIP	Programme Implementation Plans
PNC	Post-Natal Care
PRI	Panchayati Raj Institutions
PSA	Public Service Announcements
RBSK	Rashtriya Bal Swasthya Karyakram
RCH	Reproductive and Child Health

RMNCHA	Reproductive, Maternal, Newborn, Child and Adolescent Health
SBCC	Social and Behaviour Change Communication
SDMC	School Development and Management Committees
SHG	Self Help Group
SMS	Short Message Service
SNCU	Special Newborn Care Units
SSA	Sarva Shiksha Abhiyan
TV	Television
UNICEF	United Nations Children's Fund
VHND	Village Health & Nutrition Day
WHO	World Health Organization
ZP	Zila Parishad

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About the Report

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

Deloitte developed this Report into two parts: This is Part 2 of the Report entitled '*National Communication Framework for RBSK*' and is informed by the analysis and findings from *Part 1: Formative Research Report*. It is presented as a first part to this Report. This report 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, and implementation framework, and capacity development of supply-side functionaries.

The '*Formative Research Report*' 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 towards children with birth defects and developmental delays. It also covers the systemic and operational gaps in implementing RBSK, capacity development needs of the supply-side functionaries.

Introduction

Child Health

With a child population (up to 18 years of age) of over 400 million, India has the largest number of children in the world. Child health indicators in India, however, continue to be a cause of concern. An estimated 26 million births take place in India every year. However, under-five child mortality is 1.27 million children per year, of which 81%¹ takes place within one year of age. India's contribution to global child deaths is a significant 20%.² A substantial 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.³

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 including Universal Immunisation Programme, RCH I, RCH II under National Health Mission, RMNCH+A approach under NHM. All these programmes were introduced to address the major causes of child mortality and delays in accessing and utilising health services. The National Health Mission's Child Health interventions addresses child health and survival using a Continuum of Care approach, providing health interventions across a child's lifecycle.

Rashtriya Bal Swasthya Karyakram (RBSK)

Along with efforts to reduce child mortality, the focus on improving survival outcomes became equally important. 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 Child Health Screening and Early Intervention Services initiative (*'Rashtriya Bal Swasthya Karyakram'*) in 2013 to provide targeted, comprehensive care to children aged 0–18 years. Screening of all children was meant to give opportunity of early intervention in conditions like congenital cardiac diseases, congenital cataract, among others. Under RBSK, children aged 0-18 years are screened for 4Ds - defects at birth, diseases, deficiencies and developmental delays including disabilities.

As 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 (AWCs) at least twice a year, and of children aged 6 to 18 years at school. A dedicated workforce, Mobile Health Teams (MHTs) comprised of two AYUSH doctors, one ANM/staff nurse, and one pharmacist, conduct screening for children at schools and AWCs.

Children screened and diagnosed with a health condition (within 4Ds of RBSK) 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 if DEICs are yet to be set up. These DEICs are the first referral point for further evaluation, treatment and management and provide referral linkages to designated secondary/ tertiary health facilities.

¹ Child Health Background, National Health Mission

² The Situation of Children in India – A Profile, UNICEF

³ The Situation of Children in India – A Profile, UNICEF

Need for the Study

While the programme exists to screen, evaluate and treat children with 2Ds, India does not have a surveillance system to examine 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 and institutional stakeholders.

While there are other health programmes in place to address the diseases and deficiencies, interventions to address birth defects and development delays including disabilities (2Ds) are covered only under RBSK. As a result, a formative research focusing on birth defects and development delays was essential 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 the lead technical partner in India for Newborn and Child Health, UNICEF in India has been involved in RBSK among other Government of India's Child Health programmes, especially for development for branding materials. The C4D team of UNICEF has developed a short film on 'RBSK' to highlight the importance of the programme in minimising disability through early intervention. The C4D team also provided support in development of branding materials for RBSK vehicles, RBSK brochures, posters and display boards for DEICs. However, before launching the full-fledged SBCC Framework, it was important to have experiences and learning from the field of caregivers of children with 2Ds. An effective communication framework requires evidence and data to guide it.

Methodology

UNICEF engaged Deloitte India to conduct a formative study on caregivers of children with 2Ds. This study was meant to bridge the gap on the social norms, knowledge, attitudes, practices and health-seeking behaviours, and barriers faced by caregivers of children with 2Ds and community members. This study sought inputs from a wider range of stakeholders including individual caregivers having children with 2Ds to networks, communities and service providers. This builds on the insights and perspectives gained from the field including 878 in-depth interviews with caregivers of children with 2Ds, and focus group discussions with over 170 community members, frontline workers, and formal/informal groups. In addition, the Capacity Development Framework draws from discussions held with institutional stakeholders including 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. In particular, meetings with the IEC Officials in different States were useful to understand their perception of 'IEC/SBCC' as well the existing structures within which this Framework can be integrated and implemented. The process of developing the National Communication Framework was based on a sound understanding of the community-based needs of caregivers of children with 2Ds, community members, and health system and institutional stakeholders rather than a top-down information dissemination approach.

This evidence-based, National Communication Framework for RBSK, engrained in a right-based programming framework, is aimed at targeting and overcoming awareness, attitudinal, and barriers related to accessing RBSK services. This Framework uses a Socio-Ecological Model, reflecting a shift from a focus on the parents (usually the mother) alone to recognising that a range of family, community members and social, political networks (policy makers, community and service providers) influence behavioural outcomes. Recognising the fact that this Communication Framework feeds into an on-going Child Health Programme under National Health Mission, the Framework uses the four key principles of the Convention of the Rights of the Child (CRC) including (i) non-discrimination, (ii) the best interests of

the child, (iii) the right to survival and development, and (iv) participation, with all rights applying to all children at all times.⁴

Purpose of this Report

This framework is not prescriptive in nature. The purpose of this National Communication Framework is to serve as a guidance to support advocacy and communication interventions at the National and State level to achieve RBSK goals. The formative study covered 5 States across the country and reflects the ground realities across the country. However, the cultural nuances across and within States in India necessitate customisation of the National Communication Framework to suit the needs of each State.

Structure of this Report

The National Communication Framework on RBSK includes:

- Situation Analysis
- Implications for Communication Framework
- Conceptual Model
- Barrier Analysis
- National Communication Framework for RBSK
- Key Audiences
- Communication Approaches
- How to Implement the National Communication Framework for RBSK
- Capacity Development
- Suggested Implementation Framework

⁴ http://www.unicef.org/crc/index_30177.html (Rights under the Convention on the Rights of the Child), UNICEF Accessed 22 June 2016

Situation Analysis

Magnitude of 2Ds among children in India

Over the past decade, there has been a decline in the under-five mortality rate in India from 126 per 1000 live births in 1990 to 49 per 1000 live births in 2013. Although, India missed its Millennium Development Goal (MDG) 4 of reducing child mortality rate by two-thirds, the progress in child health has been commendable. Further reduction and prevention of child mortality demands due attention be given to birth defects prevention.

Current situation and burden of birth defects

Birth defects, or congenital anomalies, are structural or functional defects that arise before birth. Per the March of Dimes (MOD) Global report on birth defects (2006), it is estimated that nearly 8 million children worldwide are born with a serious birth defect of genetic or partially genetic origin. According to the joint World Health Organization (WHO) and MOD report, birth defects account for 7% of all neonatal mortality and 3.3 million under five deaths. This is owing to poor status of women's health and nutrition, inadequate care during pregnancy, and childbirth and social determinants including poverty, high fertility, and greater frequency of consanguineous marriages.⁵

Major birth defects include congenital heart defects, Neural Tube Defects (NTDs), Down syndrome, hemoglobinopathies and glucose-6-phosphate dehydrogenase deficiency, cause 20% of infant mortality and are responsible for a substantial number of childhood hospitalizations. It has been estimated that 70% of the birth defects are preventable.⁶

The actual burden of birth defects is not known in India due to inadequate epidemiological information. In India birth defects prevalence varies from 61 to 69.9 per 1000 live births.⁷ 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 into 1.7 million birth defects annually accounting for 9.6 per cent of all newborn deaths.⁸ India's focus on prevention of infants being born with birth defects have focused on strategies including iodization, double fortification of salt, flour fortification with multivitamins, folic acid supplementation, periconceptional care, carrier screening and prenatal screening.⁹ Babies with serious birth defects, are now able to survive with advancements in medical technology and health services, increasing the number of infants and children with lifelong disabling conditions. Such children require long-term medical and supportive interventions, putting an additional burden on stretched health systems.¹⁰

⁶ World health organization. Management of birth defects and haemoglobin disorders: Report of a Joint WHO-March of Dimes meeting. Geneva, Switzerland, Geneva: WHO; 2006

⁷ 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

⁸ March of Dimes Report 2006

⁹ Sharma, R. Birth defects in India: Hidden truth, need for urgent attention, Indian Journal of Human Genetics, 2013

¹⁰ Regional communication strategy for the prevention and control of birth defects, World Health Organisation, 2015

Current Situation of Developmental Delays

Functional birth defects, often related to a problem in working of a body part or system, lead to developmental delays including disabilities. An estimated 3.2 million children born globally who may survive, may have a lifelong mental, physical, auditory or visual disability.¹¹ Few risk factors for these include genetic defects (such as Down Syndrome), fetal alcohol syndrome, perinatal factors and severe medical conditions soon after birth including birth asphyxia, and others associated with prematurity. Several social determinants are associated with developmental delays and disabilities such as poverty, poor maternal health and nutrition; poor care during pregnancy and childbirth, and lack of early stimulation.¹²

In India, 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 New-born Care Units (SNCUs) were found to be suffering from developmental delays or disabilities at a later age.¹³ Developmental delays including disabilities in the first five years significantly hinder the growth potential of the child. It may reflect the child's need for a special interdisciplinary care, treatment or other services that are lifelong or extended duration, usually planned on a case-to-case basis.

With a strong grounding in population health and well-being, RBSK shifts away from viewing birth defects and developmental delays including disabilities only as a medical problem with a primary focus on screening, and early intervention for children with 2Ds. This view changes the focus from rehabilitation approach to a public health approach framed in terms of reduction of risk factors and early identification of children with 4Ds to prevent the onset of disability.

Knowledge, Attitudes, Practices of Caregivers of Children identified with 2Ds

With limited epidemiological and social research data on children with birth defects, and developmental delays, the formative study explored the knowledge, attitudes, beliefs, and practices of community members and caregivers of children with 2Ds. The detailed findings can be accessed under a separate report on '*Formative Research Report on RBSK*'. The major highlights are summarised below:

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 2D, normal children, and newborns. The study had 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 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%), followed by club foot (22%), and cleft lip/palate (13%). Among delays, the top three found in the study was language delays (27%), followed by visual impairment (22%), and hearing impairment (12%).

Knowledge of health conditions of children with 2Ds and RBSK

Caregivers' knowledge is crucial from a communications perspective and to target awareness generation activities. Caregivers were unaware of any technical or medical details of their child's condition. For children with visible birth defects, caregivers gave a vague explanation such as '*the child's legs are not okay and he can't walk properly*' or '*a hole in the heart*'. For developmental delays, caregivers are only able to describe it in terms like '*brain is not developed*' or '*body is weak*', indicating limited understanding

¹¹ Neonatal – perinatal database and birth defects surveillance, Report of the regional review meeting, New Delhi, World Health Organisation, SEARO (2014)

¹² Gulati S and Wasir, V. Prevention of Developmental Disabilities, Symposium on Developmental and Behavioural Disorders, All India Institute of Medical Sciences, India Journal of Pediatrics (2005)

¹³ Operational Guidelines on RBSK, Ministry of Health and Family Welfare (2013)

of the condition. This could be owing to the poor educational attainment of 75% of caregivers (38% of respondents were non-literate, another 37% of caregivers had completed primary level of schooling).

Further, 40% of caregivers of children with easily observable birth defects are able to know of the condition at birth. Whereas for children who develop developmental delays that take time to manifest, only 15% caregivers knew of the child being different at birth. This distinction is evident from the exhibits below.

Exhibit 1: Percentage distribution of caregivers' awareness about the child's condition, having birth defects

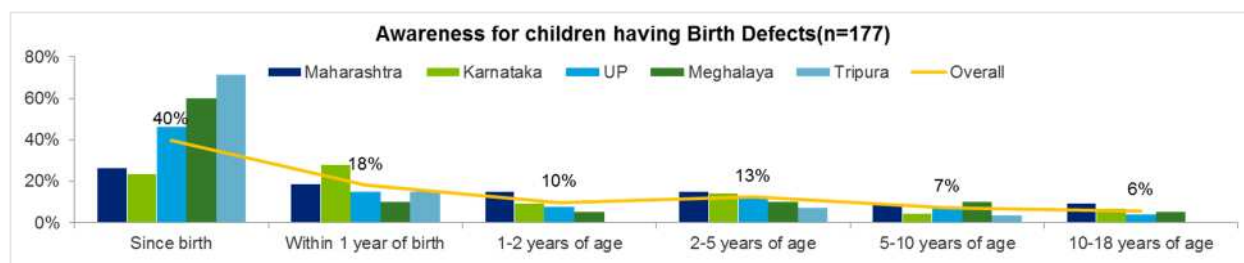
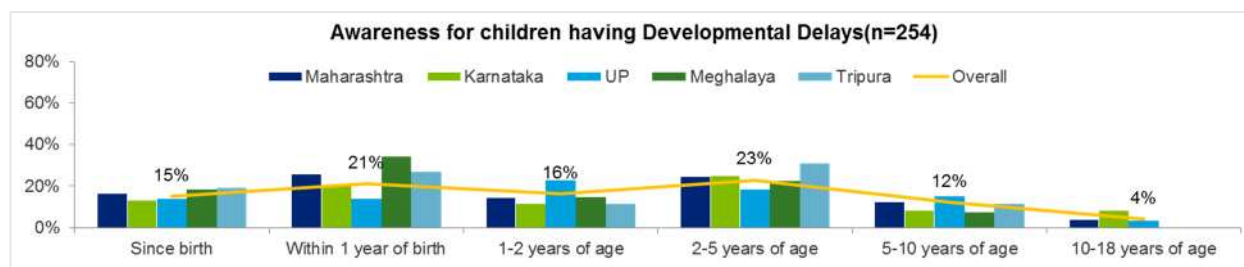


Exhibit 2: Percentage distribution of caregivers' awareness about the child's condition, having developmental delays



With respect to awareness of RBSK, 55% of the caregivers indicated knowing about the programme measured through their awareness a team of doctors coming to the schools and Anganwadi centres to conduct check-up children. The awareness was higher in States such as Maharashtra (38%) and Karnataka (24%). The source of this information was frontline workers including AWWs (55%), ASHAs (32%), and school teachers.

However, most caregivers had very limited knowledge of RBSK's rationale and continuum of care. Probing on in-depth responses revealed that they were not clear about what the check-up (or screening) meant, and did not understand the potential benefits of screening and early intervention.

Attitudes and Beliefs of Caregivers towards Children with 2Ds

Attitude measures general attitudes of children with special needs (CWSN), responses of caregivers when they know of their child's condition, response of community members, and front line workers towards families having children with 2Ds.

Largely positive stance towards children with 2Ds, or children with special needs

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. The vignette measured general taunts by mothers-in-law, 56% of the caregivers 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. Moreover, interviews with mothers-in-law revealed that they tended to be supportive and partake in caring for the child with special needs, often accompanying their daughters-in-law to the health facility, if required.

62% of the respondents felt that it would be easier for caregivers like 'Kamla' to deal with 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.

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.

With respect to response of community members and frontline workers, nearly 32% of the caregivers received encouragement from their community members to seek medical care. Additionally, 24% of the parents/caregivers of children with 2Ds also felt that community members were sympathetic towards them. More than 40% of respondents felt that ASHAs and AWWs were only playing a role in provision of information, and often offer verbal solace.

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

Most parents interviewed for the study perceived that RBSK screening was not offering medical care since no medicines were dispensed to address immediate health conditions such as fever, cough, diarrhea, among children. Caregivers are not be able to distinguish between medical conditions associated with birth defects and development delays, 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.

Caregivers pin their hopes on medical care and possess right set of beliefs

The study revealed that caregivers had belief in medical care and 80% of them were hopeful that their child could be cured. While there were a few caregivers who were fatalistic, a large proportion of caregivers were willing to access care, despite facing financial, transport and other barriers. Nearly 25% of caregivers met did not know the cause of their child's condition.

55% of the caregivers attributed the cause of the condition of their child to poor health seeking behaviors during pregnancy and childbirth. Only 10% of the caregivers attributed their child's condition to God's wish, black magic, past deeds, or other inauspicious events that are outside their control.

Practices

Preference towards private sector

It was observed that most 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. Nearly 16% of parents sought treatment at government health facilities. Only 7% of parents tried alternative forms of therapy such as traditional healing, Ayurveda, etc.

Joint decision-making was common

Further, 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 done by the parents together

Barriers

Finance and Transportation, two most commonly faced barriers by caregivers of children with 2Ds

More than 50% caregivers identified finance as their 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. Additionally, 21% of caregivers expressed that transport was a key barrier they faced, in reaching a health facility. Cognitive barrier was also observed, 13% of caregivers identified lack of information regarding child's condition as an impediment to treatment. Further, psychological distress as a function of constant caregiving for children having 2Ds is also another barrier faced mostly by mothers.

Enablers

Several enablers or facilitating factors to motivate caregivers to avail RBSK services and improve utilization of the programme were identified. They include:

- Building awareness of RBSK and the importance of early intervention
- Complementary health insurance schemes that also cover RBSK conditions to address financial barriers of caregivers
- Introducing a mechanism wherein transport to health facilities is covered or provided, either through RBSK itself or other health programmes
- Creating a positive experience with the programme for patients and families

Findings from Health Department Officials and other Department Officials

Detailed 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 given to RBSK among senior bureaucrats in States

With the multitude of programmes under National Health Mission, perceived importance of RBSK among senior bureaucrats and focus on the RBSK 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 strongly for the programme with other officials.

Further, limited focus on the programme is further demonstrated by the slow progress made in RBSK training. This poor focus on the programme has led to slow programme implementation. For example, screening by ASHAs at home and MOs in delivery points yet to pick up. Further, there has been slow progress on operationalization of DEICs. This, in turn, affects successful delivery of the programme, and creates reluctance among beneficiaries to use its services, especially the follow-up and tertiary care services.

Weak referral system impeding evaluation and management of children screened to have 2Ds, limited knowledge of RBSK among service providers at PHCs/CHCs/DHs

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.

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 of launch of the RBSK, the operationalizing of DEICs has been quite slow.

Public health facilities not sufficiently geared up to receive parents for follow-up and care

Public health facilities lack the necessary diagnostic infrastructure/equipment 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.

Lack of mapping of tertiary/secondary care services impeding programme success

Many Health Department officials felt constrained by inability to act due to absence of Memorandum of Understanding (MoUs) with private sector/ government sector (medical colleges). Officials did not have a clear guidelines/mapping of secondary/tertiary care institutions for evaluation/management of 2Ds available in the State. Without this mapping, the programme was unable to deliver outcomes beyond screening phase. Even within screening phase, instead of a focus on quality screening, a target-driven approach to screening is being followed. Additionally, a few District officials were noted to have limited understanding of the meaning of “early intervention” under RBSK in minimizing disabilities.

Involvement of other Department Officials, and consequently convergence is weak

Limited sensitization of officials in other departments at State/ District/ Block levels on RBSK. As a result of poor convergence mechanisms, especially at State and District levels, the awareness of RBSK is low among officials of other departments.

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. The IEC/ BCC activities are being limited to printing registers and referral cards.

Several trainings needs emerged for different officials and service providers

Overall financial utilisation for RBSK training is poor with the exception of Maharashtra (50% of training budgets have been utilised in 2015-15). MHTs in UP are yet to receive the 5-day RBSK training to screen

children. Further trainings for MHTs have largely been technically focused, with no attention being given to soft skills including IPC and counselling skills.

Service providers in these public health facilities including DHs/CHCs/PHCs do not possess the complete understanding of RBSK and its associated health conditions. A detailed capacity development measures have been proposed in the chapter on Capacity Development.

Findings from MHTs and FLWs

Mobile Health Teams play a crucial link between the community and health system

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'. In the absence of mapping of services available in the State/District, many of the MHTs are not aware on where to send children with developmental delays. This was seen as a major service delivery challenge in the absence of DEICs.

While there is no formal mechanism for follow-up with caregivers, follow-up is being done by MHTs 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.

Frontline workers role play a limited role in the programme

FLWs are trusted source of information for families about health programmes. In particular, Anganwadi Workers (AWWs) play a crucial role in provision on screening dates and arrival of MHTs. In some cases, caregivers have gained a lot of emotional support from frontline workers. However, frontline workers were found having limited knowledge of RBSK, and rationale for the programme. Many of the frontline workers including AWWs who are involved in the community mobilization have not received any formal trainings. ASHAs have a limited role in RBSK delivery, especially since home-based screening for newborns has not yet been rolled-out.¹⁴

The next section expands on the findings to delineate key implications for the Communication Framework.

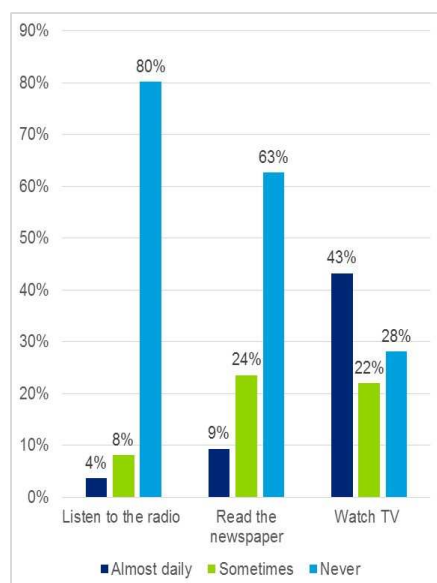
¹⁴ As of July 27, 2016

Implications for Communication Framework

Communication specific profile of caregivers of children with 2Ds

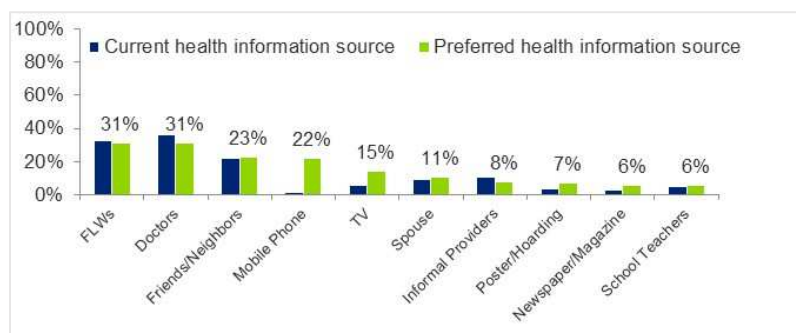
Mass-media campaigns have long been used as a tool delivering preventive and behaviour change health messages. Hence, the caregivers study tool had a component on communication channels to understand media consumption habits. As depicted below, television has the highest preference on a daily basis, with over 40% of the respondents watching television on a daily basis. In comparison, the newspaper and radio are not preferred sources within mass-media. While only 24% of the caregivers reported reading the newspaper on a daily basis, majority of the semi-literate caregivers stated that they used newspapers to find about 'free medical camps' and other health-related information.

Exhibit 3: Frequency distribution of media consumption habits



In response to a range of current sources of health information, 36% of caregivers said they got their health information from doctors and another 33% respondents from their frontline workers. A similar response was obtained for future sources of health information as well. Given that the rural mobile subscriber base is nearly 42%¹⁵, it is not surprising that 22% of the caregivers in this study also expressed their desire in receiving health information messages or alerts through a cellular phone.

¹⁵ TRAI, New Delhi, September 2015, Accessed 22nd June, 2016

Exhibit 4: Current v/s Preferred Sources of Health Information

Based on the situation analysis and the detailed formative research findings, a list of implications for communication framework have been developed and presented below:

Implications for Communication Framework

Using information as a means to improve RBSK outreach

In order to change behaviors around screening, it is important to address the knowledge of the parents / primary caregivers. As was observed in the study, many parents do not possess correct / complete information about screening. They do not understand screening and consequently early intervention as a way of detecting and minimizing disabilities for children with 2Ds.

A large majority of respondents were emotionally disturbed after becoming aware of their child's condition. Majority of them neither knew the details of the condition nor could explain it in technical and medical terms. They had a limited understanding of the problem – such as brain being weak, or body being weak (depending on the nature of defect or delay).

Furthermore, our study indicated that even teachers and Anganwadi Workers (AWWs) were not aware of the objective of RBSK, even though they are directly involved in the programme.

Communication Standpoint

- Communities need to be given information on screening date/venue through Public Service Announcements, or newspaper ads so that they are aware of when the RBSK teams come for screening. Counseling parents of children screened with 2Ds about the importance of early intervention and evaluation can enable them to avail treatment for children and benefit from RBSK. Use of pictorial booklets and IPC by ASHA could help
- Orientation workshops should be conducted for all teachers and Anganwadi workers and they could be given a small booklet to refer to later. Further, schools and Anganwadi Centers could have posters / wall-paintings depicting screening and its importance

Create a sense of community ownership of children with defects and developmental delays

Interactions with formal and informal groups at the village level across study districts revealed their interest in the programme and willingness to help in improving programme uptake. Members of Gram Panchayat (GP), SDMC members, SHG members expressed a need for the programme to be strengthened by involving community members to raise awareness of RBSK and its benefits, especially among families with children with 2Ds.

It was also observed that while families and communities were offering comfort and verbal solace to caregivers, they were not forthcoming with offering '*tangible*' support. Families need education on the importance of RBSK so that they can encourage all parents for getting their children screened. This may help communities to extend tangible support to parents such as taking care of children, etc. while parents are away for intervention and management. Communities' ownership of such children can be improved by reinforcing messages such as '*disabled children are also children of the same God and require more care and support*'. Formation of community-level support groups that offers a forum for sharing experiences can go a long way in alleviating their emotional burden.

Communication Standpoint

- Community norms regarding support can be targeted through mass-media efforts such as TV ads and radio jingles. There could be an effort to form community groups to help parents of children screened to have 2Ds
- Members of formal and informal community groups can be leveraged for community mobilization activities, to spread awareness of the programme and help change the mindset of the community towards improved health seeking behaviour. 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. These groups could also play a role in providing tangible support to families, for example, by organizing small community loans or bringing people together to form support groups
- Communication needs to empathize with the emotional burden on the mother – especially the psycho-social aspect. This could be addressed by leveraging an existing toll-free helpline or through IPC/counseling from AYUSH doctors. Support networks such as mothers groups' with children with 2Ds could be formed to provide emotional support and persuade mothers for early intervention, physiotherapy, follow up treatment, etc.

Capitalize on the 'hope' factor

The study revealed that parents had belief in medical care and were 'hopeful' that their child could be cured. While there were a few parents who were fatalistic, a large proportion of parents were willing to access care, despite facing financial, transport and other barriers. RBSK could improve programme utilization by providing them with services at their first-point-of-referral. When parents reach PHC/CHC/DH/DEIC, they should be received well by public health providers.

Communication Standpoint

- There should be weekly evaluation and management sessions at PHC/CHC/DH where health providers are readily available to receive parents of children and offer services with utmost care and quality. This can help caregivers in regaining the trust in the public health system
- Additionally, a kiosk / helpdesk to guide parents and help them navigate the hospital, may also facilitate

caregivers to return for follow-up visits

Changing attitudes of caregivers from 'cure to care'

Most parents interviewed for the study perceived that RBSK screening was not offering medical care since no medicines were dispensed to address immediate health conditions such as fever, cough, diarrhea, among children. Caregivers may not be able to distinguish between medical conditions associated with birth defects and development delays, as well as the nature of treatment or caring practices for the 2Ds. For instance, as was observed in the findings, parents both Down syndrome and neuro-motor impairment as 'brain is weak (*'dimaag kamzor hai'*). They are unable to distinguish between approaches of care or cure that may be possible for a variety of conditions covered under RBSK.

Communication Standpoint

- Proper training of all medical officers at PHC/CHC/DH needs to be carried out in the short-term to ensure that parents get a warm reception at the facility. During the evaluation sessions, MOs can provide counseling to the parents on the type of condition and what treatment / management options exist for the child.
- Counseling and educating of parents should emphasize on the fact that 'screening' is the first step towards providing long-term care and cure for children. The idea of 'care' vis-à-vis 'cure' needs to be repeatedly communicated to parents and families. It is imperative to use this touch point with parents to highlight the importance of early intervention for children identified with 2Ds. Here, the providers need to be given training on the level of difficulty / waiting expected in accessing services for each defect or developmental delay. In the case of developmental delays that may require long-term care rather than cure, caregiver education and emotional support is required. Cost burden of long-term care that may not be covered by the programme is a major barrier for most families

Addressing mistrust in the public health system

Most of the caregivers took their children to private health facilities. This was due to their negative experience in the government health facilities or difficulty in accessing treatment services after referral. In many cases, parents had directly approached the private health system for their children with visible birth defects as they believed it offered quicker response time and better quality of care. Further, since RBSK MHTs go to the community to conduct screening, parents' expectations of the programme is heightened. When the system is unable to cater to the demands, parents further lose faith in the system affecting the utilization of RBSK. Caregivers are not being persuaded from the public health system to come for repeated follow-ups and they lose motivation to come back to public facilities.

Communication Standpoint

- Ensure that all MHTs/MOs dealing with the RBSK beneficiaries empathize with caregivers' emotional burden, financial stress and long-term care that tends to be associated with children with 2Ds. Public health system could have kiosks at facilities to receive RBSK parents and toll-free helplines to address the parents' queries. Having functional DEICs with quality services available could go a long way in serving needs of the caregivers with 2Ds

Utilize the communities trust in frontline health workers

FLWs are trusted and inform families about health programmes. They are the main source of information about screening camps and arrival of MHTs. In some cases, caregivers have gained a lot of emotional support from frontline workers. This communication channel can be strengthened to act as a facilitating factor in generating demand for RBSK. However, FLWs themselves lacked knowledge of RBSK, especially screening and early intervention.

Communication Standpoint

- Ensure all FLWs are trained and motivated to deliver the program on the field. FLWs can be used to provide information and emotional guidance and support. AWWs / School teachers can also reinforce messages to the parents and mothers-in-law through persuasive counseling

Leveraging the wide network of informal service providers to provide information on RBSK especially in areas with difficult terrains

Our study observed that it is common practice for rural households in developing countries, including India, to rely heavily on informal healthcare providers (IPs) as their first-point-of-care for most ailments. Most parents had gone to their village doctors/IPs to consult them on their child's health because they are easily available, and accessible, allowing patients to save on time and cost of travel. In addition, IPs tend to charge nominal amounts and even dispense medicines so parents are able to avoid the cost of both travel and buying medicines. They don't incur wage loss as IPs tend to have flexible working hours that are suited to the needs of the communities. The parents also tend to trust IPs as they belong to the same community (this was particularly observed in Tripura and Meghalaya). Our study found that most IPs had children with birth defects and developmental delays come to them; however, they were unaware of government programmes such as RBSK that cater to the needs of such children. IPs also had a positive attitude towards medicine, and often, directed these parents of children who required surgical interventions to seek care under the formal medical system.

Communication Standpoint

- As traditional healers are often 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 the programme. 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 be used to provide families with information on the importance of screening, and early intervention to minimize disability and for RBSK

Integrate awareness on preventing birth defects and developmental delays into other programmes

Our study observed that it is common practice for many communities in southern India to marry within the families (consanguineous marriages). Similarly, the study also found that many pregnant women were involved in heavy labor intensive field work, and did not get complete antenatal check-ups done. Many studies including reports from WHO have established the importance of ANC care including micronutrient deficiency management to prevent children from being born with birth defects.

Communication Standpoint

- Adolescent health programmes (Rashtriya Kishore Swasthya Karyakram) could incorporate messages around discouraging consanguineous marriages and pregnancy at advanced maternal age. Further, programmes on maternal health should reinforce messaging on immunization, supplementation of folic acid and B vitamins, prevention of exposure to tobacco and alcohol, discouraging self-medication during pregnancy, etc.

Conceptual Model

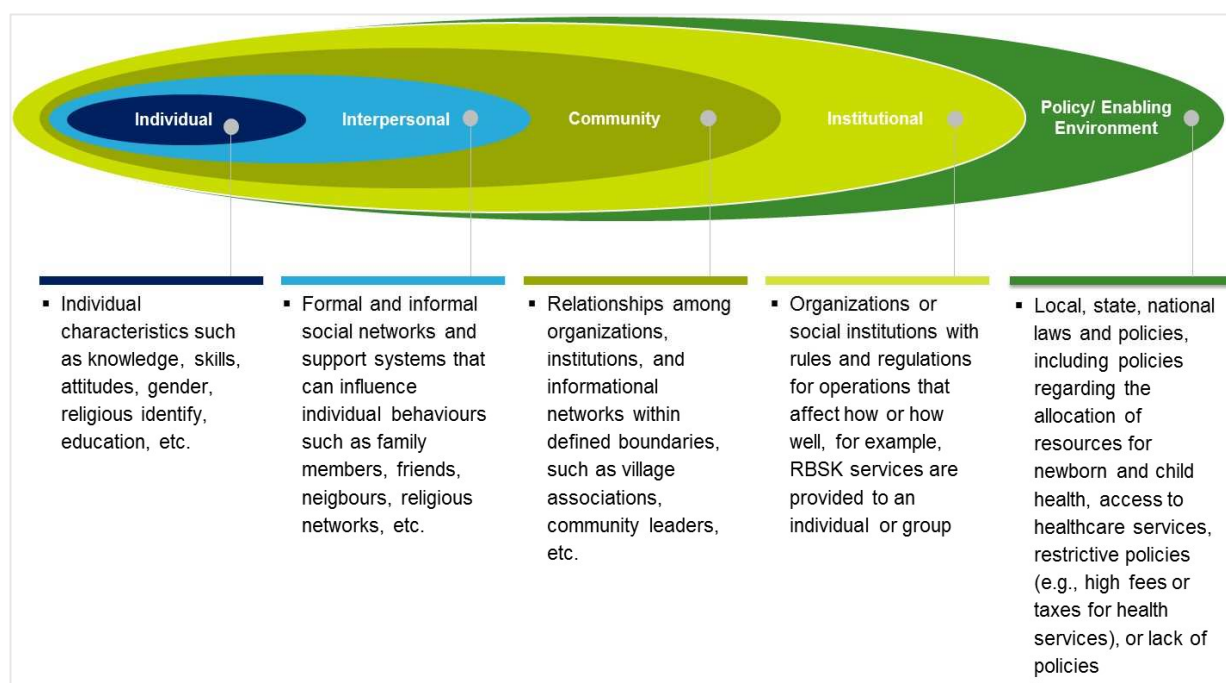
Social-Ecological Model

Various theoretical frameworks are used in the field of health promotion in order to better understand certain health behaviors or problems and to facilitate the selection and design of appropriate communication and behavior change strategies. A *social-ecological model* is important in providing a framework to understand the multiple levels of a social system and interactions between individuals and environment within this system. Mothers and children are embedded within networks, communities and systems. The barriers to healthy behaviors often lie beyond the individual in the family, within the interpersonal network, community, and societal culture or even within the health system.

Therefore, an RBSK communication framework that uses a social-ecological model recognizes the multiple determinants underlying any health condition or barriers at different levels that impede desired health behaviors, especially for something as complex as birth defects and developmental delays in child health. A communication strategy that is informed using such a framework will be more relevant and effective in bringing about change. And, although it is necessary that we educate individual mothers about RBSK issues and behavior change, that alone will not be sufficient to improve overall outcomes.

What may be necessary and sufficient is to address the multiple barriers to behaviors that lie at different levels of the social-ecological system in which the mother and child live. Effective RBSK communication framework will therefore use this social ecological model to identify key audiences at different levels – at interpersonal level it could be the mother-in-law, at organizational level it could be the district hospital staff and so on.

Using the social ecological model as a conceptual model, this RBSK communication framework helps identify behavioral and organizational leverage points and intermediaries for health promotion within organizations. There are five nested, hierarchical levels of the social-ecological model: Individual, interpersonal (household), community, organizational, and policy/enabling environment (see exhibit below). The most effective approach to public health prevention and control uses a combination of interventions at all levels of the model.

Exhibit 5: A depiction of different levels of the Socio-Ecological Model

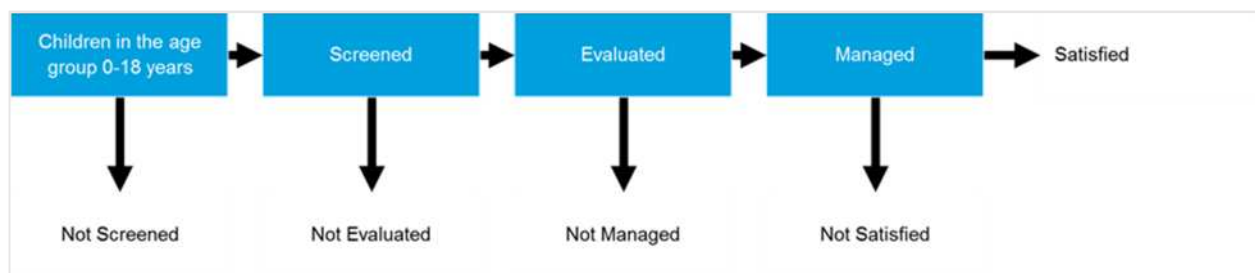
The socio-ecological model recognizes that caregivers are nested within families, communities, organizations, societies; and that these varied loci of existence shape health behaviors. This approach allows us to recognize factors at each of the levels within an individual's environment and encourages us to integrate system-wide interventions with person-focused efforts to modify behaviour and/or environments.

This model guided the analysis of from the formative study on defects and delays among children in RBSK. The framework helped to identify the barriers for behavior change and classify them at their level of existence within the primary caregivers (audience) environment. These barriers have been adapted to the four broad levels: individual, family / household, community, and organizational. These have been described in detail below in greater detail, thus allowing for a better understanding of the caregivers and how to move them towards behaviour change using a strategic communication approach.

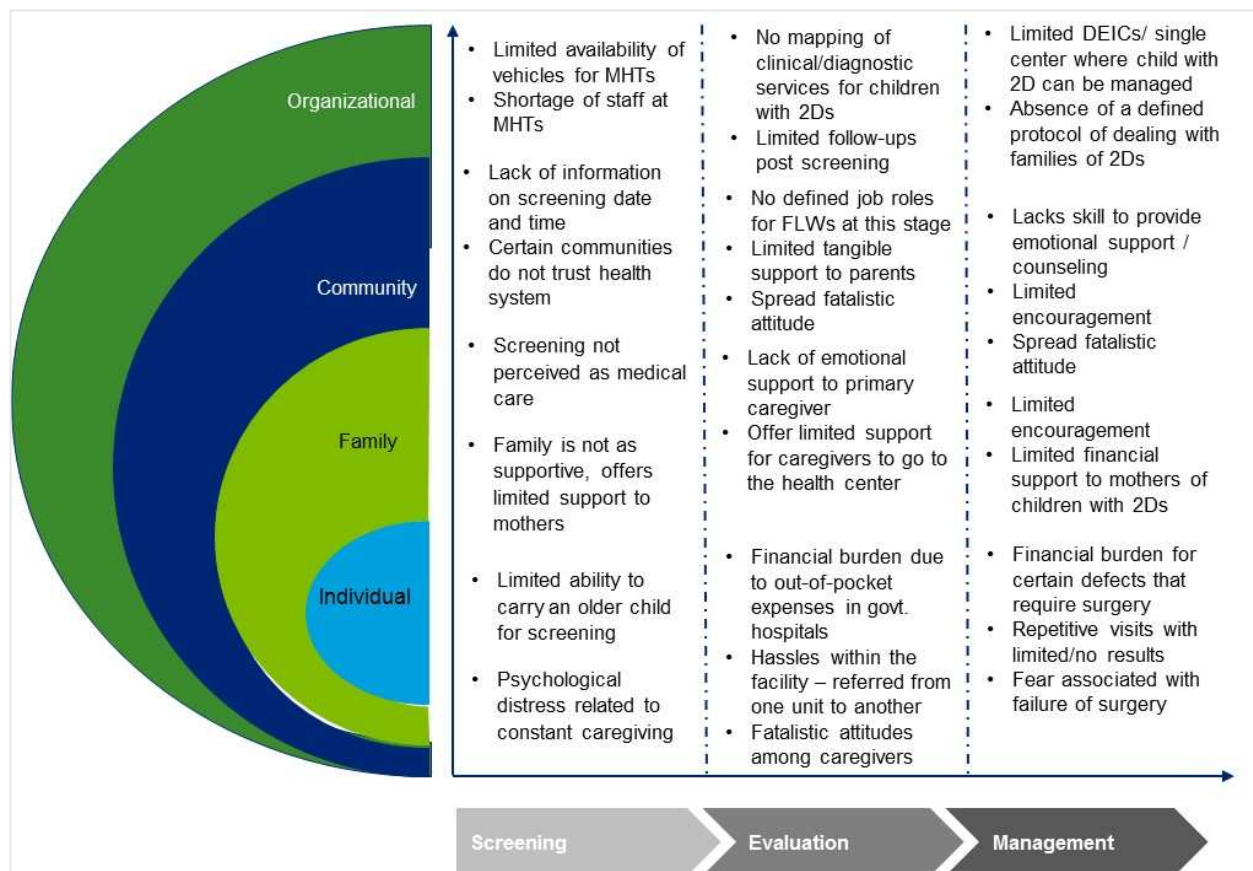
Barrier Analysis

A key focus of this study was to understand the barriers faced by the caregivers of children with 2Ds. Based on the 878 in-depth interviews, an attempt has been made to analyze and categorize these barriers across the continuum of care experienced by a child with a 2D screened under RBSK. The key steps of this continuum, as well as the junctures at which children drop-out of the system, are depicted in the exhibit below:

Exhibit 6: Continuum of care under RBSK



The barriers have been categorized using the steps of the continuum as shown above. Additionally, the barriers have also been categorized based on the systemic level at which they exist as a barrier for caregivers, based on the social-ecological framework introduced above. A sample graphic of how the two frameworks have been superimposed is shown below:

Exhibit 7: Illustrative Barrier Analysis

Using the two variables of continuum of care and systemic level, a two-by-two matrix has been used to analyze key barriers faced by caregivers in detail, provided below:

Table 1: Barriers related to accessing RBSK analysed using Socio-Ecological Framework

LEVELS	BARRIERS TO SCREENING	BARRIERS TO EVALUATING/ INTERVENING EARLY	BARRIERS TO MANAGEMENT OF CHILDREN WITH 2Ds
ORGANIZATIONAL (State/ District)	<ul style="list-style-type: none"> Limited availability of vehicles for MHTs Shortage of staff at MHTs Unrealistic targets for screening New born screening not started Vacant positions for AYUSH in MHTs Limited training of RBSK staff 	<ul style="list-style-type: none"> Limited DEICs / single facility where all screened children can be evaluated for confirmation of condition No clear mapping of tertiary/diagnostic services/treatment options in the district/state DH/CHC medical fraternity lacks detailed information on RBSK Out-of-pocket payment for diagnostics Referrals to multiple centers to get diagnosis done Limited arrangement for transportation of caregivers (and money spent on transportation) Poor institutional arrangement for accommodation, food, and other related aspects for caregivers 	<ul style="list-style-type: none"> No clear mapping of tertiary/diagnostic services/treatment options in the district/state Limited information given to parents on the process of management of children with 2Ds Lack of DEICs / single center where child can be managed Lack of requisite skilled manpower (or rehabilitative care experts) to manage children with 2Ds Limited arrangement for transportation of caregivers (and money spent on transportation) Poor institutional arrangement for accommodation, food, and other related aspects for caregivers Absence of a defined protocol of dealing with families of 2Ds and poor information and counseling for parents Camp-based approach for provision of care could lead to certain parents missing out on the services (e.g., if they are unable to come to the camp) Non-availability of specialists to offer services for children who often require specialized care Non-availability of treatment for certain conditions
ORGANIZATIONAL (Block Administrative)	<ul style="list-style-type: none"> Limited availability of vehicles No process available to verify children missed out in 	<ul style="list-style-type: none"> No institutional persuasion from health system to follow-up Limited availability of diagnosis 	<ul style="list-style-type: none"> Non-availability of specialists to offer services No support (accompaniment for

	<p>Anganwadi Centres (children enrolled but non-attending or non-enrolled)</p> <ul style="list-style-type: none"> ▪ Difficulty in recruiting LMO in MHTs 	related infrastructure at the Block level	<p>parents) from block level officials to the district / State capital hospitals</p> <ul style="list-style-type: none"> ▪
ORGANIZATIONAL (PHCs/MHTs)	<ul style="list-style-type: none"> ▪ Non-availability of complete screening kit/equipment not available (Snellen's Chart was missing in certain places) ▪ Availability of full and complete trained teams is a concern ▪ MHTs do not have any mandate about out-of-school children / AWC children ▪ Difficulty in conducting screening at AWCs 	<ul style="list-style-type: none"> ▪ Limited follow-ups from MHTs after screening ▪ PHC MOs, CHC MOs not giving specialized attention and care to children with 2Ds when parents come to the hospitals ▪ PHC medical fraternity lacks detailed information on RBSK 	<ul style="list-style-type: none"> ▪ Non-availability of specialists to offer services ▪ Non-availability of treatment for certain conditions ▪ Poor communication with caregivers on the concept of 'cure vis-à-vis care' ▪ Limited role for MHTs exists beyond screening while they continue to be the face of RBSK for community members ▪ Poor skills for MHTs to counsel and persuade parents
COMMUNITY (Screening Sites including AWC & School)	<ul style="list-style-type: none"> ▪ Lack of incentives leads to low participation by ASHAs ▪ RBSK does not systematically include ASHAs for community mobilization ▪ Correct information regarding RBSK not available with AWWs ▪ Teachers do not have information about RBSK ▪ Timely information on the screening event not provided to teachers / AWWs ▪ Teachers unable to mobilize out-of-school children ▪ Not all children come to AWC (reasons include migration, preference for private pre-schools) 	<ul style="list-style-type: none"> ▪ Limited follow-ups by AWWs / teachers after screening ▪ No incentives/skills to ASHAs to follow-up ▪ Limited information on available treatment/evaluation centers ▪ No defined job roles for FLWs at this stage under RBSK 	<ul style="list-style-type: none"> ▪ Limited information on available treatment/management centers ▪ Limited information on health schemes or Trusts or financial sources of help ▪ No defined role at this stage under RBSK for FLWs ▪ Lacks skill to provide emotional support / counseling
COMMUNITY (GENERAL)	<ul style="list-style-type: none"> ▪ Lack of information on screening date and time ▪ Screening not perceived as medical care because no treatment is given except IFAs, or analgesics ▪ Certain communities do not trust 	<ul style="list-style-type: none"> ▪ Limited tangible support to parents such as helping getting a vehicle, financial assistance, or looking after the remaining children when parents have to take the child for treatment ▪ Spread fatalistic attitude 	<ul style="list-style-type: none"> ▪ Limited encouragement ▪ Spread fatalistic attitude ▪ Limited tangible support to the parents such as helping getting a vehicle, financial assistance or looking after the remaining children when parents have to

	health system	Certain communities do not trust health system	take the child for treatment Limited information about Trusts / financial help sources
FAMILY	<ul style="list-style-type: none">Many children are already screened at private sectorScreening not perceived as medical care because no on-spot treatment is givenLimited support to the mother to accompany the mother & child for screeningWhen parents are away at work, family members do not take children for screening (in the case of Anganwadi centres)	<ul style="list-style-type: none">Lack of emotional support to primary caregiverOffer limited support for caregivers to go to the health centerLow support in managing household while caregiver away for the dayCynicism about public health system and free Govt. programmes / schemes	<ul style="list-style-type: none">Limited encouragementLimited financial support to mothers of children with 2DsNo support in managing household while caregiver away for the dayFinancial leakages for medical care is problematicLow information on various medical benefits
INDIVIDUAL CAREGIVER (NON-PSYCHOLOGICAL)	<ul style="list-style-type: none">Carrying an older child with severe/multiple disabilities posed as a difficultyCaregivers do not want to lose time waiting for screeningOften lack correct / complete information about screening	<ul style="list-style-type: none">Financial burden due to out-of-pocket expenses in govt. hospitals (diagnostics) incl. payment for multiple confirmatory diagnosisTransportation / conveyance hassles to the facilityDaily wage lossLong waiting time at the hospital for caregivers of children with special needs (these children can be difficult to manage depending on the condition)Hassles within the facility – referred from one unit to another (in the absence of DEICs)Referrals to multiple hospitalsLack of one point contact/helpdesk at the medical CentreLack of awareness on RBSK process and benefits	<ul style="list-style-type: none">Financial burden for certain defects that require surgeryTransportation cost to the facilityDaily wage lossLong waiting time at the hospitalRepetitive visits with limited/no resultsRecurring expenses for drugsLimited attention from medical staff for ongoing care
INDIVIDUAL CAREGIVER (PSYCHOLOGICAL)	<ul style="list-style-type: none">Limited trust in the public health system / providersPsychological distress in constant caregiving for children with 2Ds	<ul style="list-style-type: none">Fatalistic attitudes among caregiversAnxiety associated with going to the District/State Capital for medical care/evaluationFear associated with medical procedures	<ul style="list-style-type: none">Caregiver stress as the child may show limited improvements and there is need for regular care for the childFatalistic attitudes among caregiversFeelings of uncertainty and

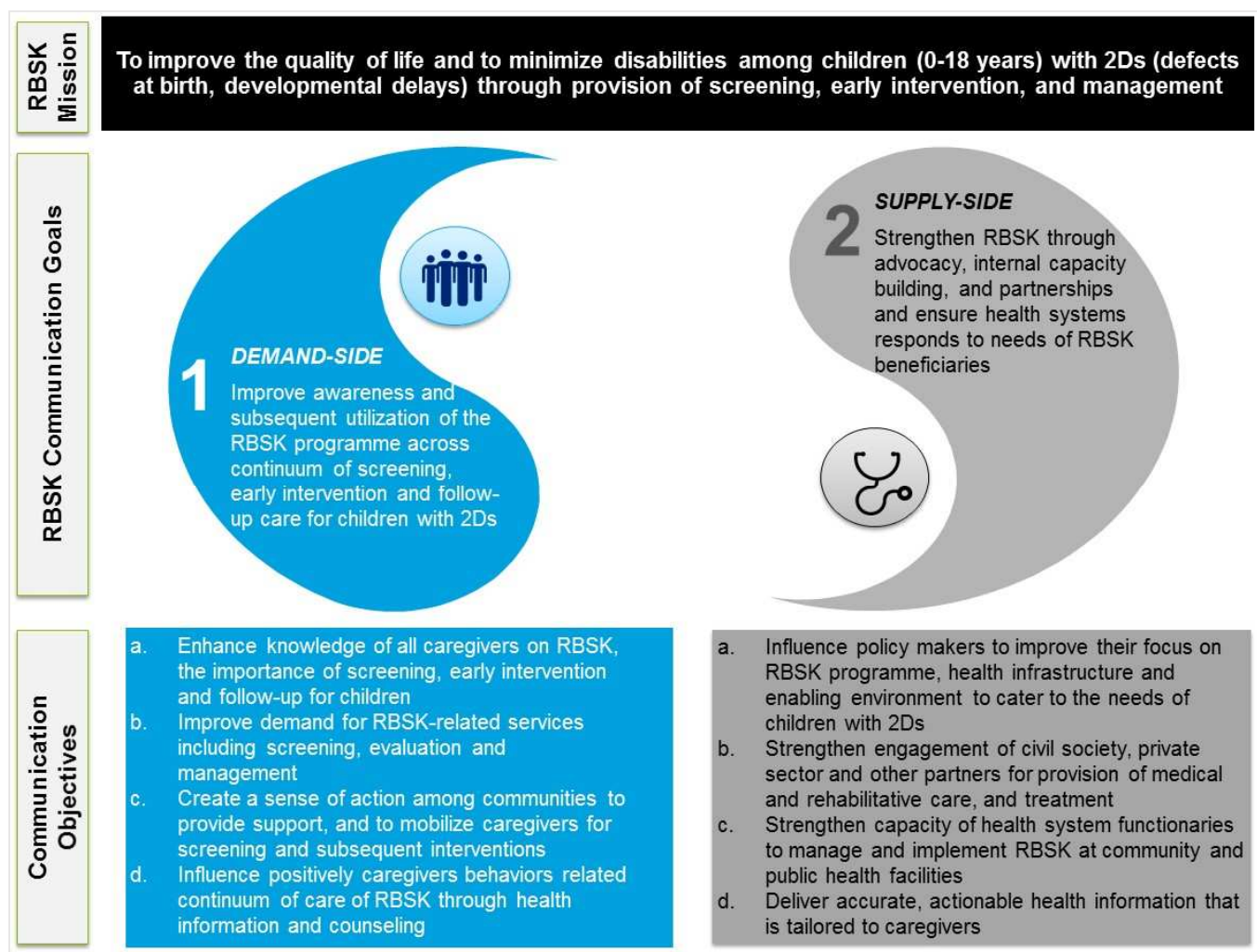
	require guarantee of healthy future of child's health
▪	Fear associated with going to the headquarters/cities for treatment
▪	Fear associated with failure of surgery
▪	Limited success after having tried multiple doctors, different treatment methods
▪	Limited trust in the medical system and giving-up on medical care in the absence of any 'cure'
▪	Perception of medicine as curative not as rehabilitative and cannot distinguish between the concept of 'care versus cure' approach
▪	Lack of emotional support from any source to endure the long-drawn process (for delays)

National Communication Framework for RBSK

Communication Goals and Objectives

Based on the evidence from the formative study, the communication framework developed is results-oriented, intrinsically linked to other programme components, responsive to the current context in which the programme operates, and favours a variety of communication approaches, to stimulate positive behaviour and social change. Findings underlie the importance of demand generation through proper education, awareness, and counseling. However, the advocacy for the programme including capacity building of health systems functionaries needs emphasis.

The overall Communication Framework is pictorially depicted below:



The overarching objective is to ensure that all families adopt desired behaviours, access and use continuum of RBSK services. Based on the broad objectives, States are required to develop their specific advocacy and communication objectives for the state-specific communication framework. For any Communication Framework to be effective it is important to identify key stakeholder groups or audiences so that the strategy can be customized to their needs.

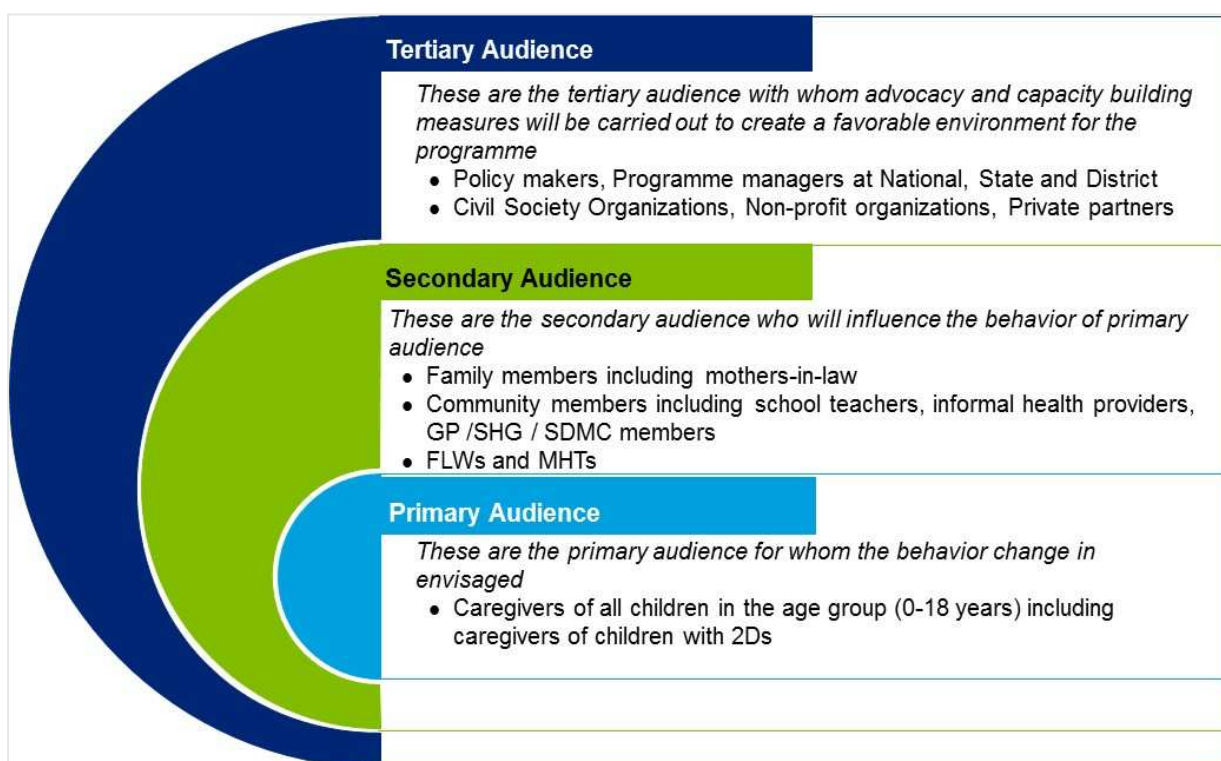
Key Audiences

Identification of Key Audiences

The purpose of the audience analysis is to identify relevant audience groups, their characteristics, and what resources each group can access to bring about and maintain the practice of desired behaviours. It describes the people to be involved in RBSK activities in order to achieve the RBSK objectives. They are also the audience in and targets of the communication framework.

The objectives of RBSK and study findings formed the basis for determining who the audience for communication should be. Different communication approaches, messages and content are needed for each of the audience groups. Identification of key audience groups allows for better designed, more focused and clear messages. For this purpose the audiences have been segmented into primary, secondary and tertiary groups as indicated below:

Exhibit 8: Audience Segmentation



Primary Audience: are those who are being directly addressed to change their behaviour. Their behaviour is an indicator of success of RBSK. In this case, caregivers of all children in the age group (0-18 years).

This also includes, caregivers of children screened and confirmed to have 2Ds. However, this also includes all caregivers with children in the age group (0-18 years) to get their children screened. Caregivers should possess the correct knowledge on screening, and be motivated to visit the higher referral centres (if the child is screened to have any of the 2Ds). Even though in this case, the child is the beneficiary for RBSK, it is important to target the caregiver's attitude and behaviour that is critical to improve uptake of RBSK. Hence, caregivers of children (0-18 years) is the primary audience.

Secondary Audience: are those whose behaviour or actions strongly influence the behaviour of the primary audience. They are usually present in immediate social and cultural environment of the primary audience. Based on the evidence and situation analysis, this includes immediate family and community members, and frontline workers such as ASHAs, AWWs, and MHTs. For example, the Mobile Health Teams that come each year for screening could explain the condition that the child is suffering from and also the rationale for early intervention to motivate caregivers of children with 2Ds. Similarly, Gram Panchayat Members could organize a community fund to motivate parents of children with neuromotor impairment to go for repeat visits including physiotherapy/speech therapy.

Tertiary Audience: Tertiary audience are those whose actions directly or indirectly help or deter the behaviours of other audience. Their actions reflect the broader social, cultural and policy factors that create an enabling environment to sustain desired behaviour change. For example, elected representatives incl. MPs/MLAs, Mission Director of National Health Mission, Officials of Health Department and service providers in District Hospitals/ CHCs/PHCs, civil society organizations (CSOs), non-profits (such as Shirdi Trust, Reliance Foundation, etc.), private sector players (including ILS Hospital in Tripura, or other hospitals who have a tie-up with the Government providing tertiary care services)

Building the Supportive Environment

Sustained change in the behaviour of the primary audience is more likely to happen in an enabling environment. An enabling environment consists of family and community, social and cultural norms, national policy, etc. Based on the Socio-Ecological Model, the Communication Framework will address behaviour change among primary audience. However, to create an enabling environment necessary for effective behaviour and social change, specific interventions on advocacy have been included in the Communication Framework.

Communication Approaches

Given that the audiences in RBSK have been analysed and key barriers to overcome have been identified, the Framework aims to consider the communication approaches to reach audiences at all levels of communication. The main communication approaches for key audience include interpersonal communication, and community mobilization, use of ICT/mobile, supported and reinforced by traditional mass-media and mid-media. There are number of ways to use approaches such as combining different media, which also promote behaviour change. For instance, mid-media (poster, flyer, and video) can be combined with IPC to make it more effective. After showing the materials, the facilitator can lead an interactive session with the audience to reinforce the messages. Hence, these components of the Communication Framework should be linked with ongoing RBSK activities such as trainings.

Interpersonal Communication (IPC)

An interactive medium, it helps in providing detailed information to the audience. It also allows for instant feedback on ideas, messages and practices. Interpersonal communication will make effective use of existing social networks or interpersonal relationships (family, FLWs, neighbours, teachers, formal/Informal groups) that bind people together to enhance the communication process. IPC is a key tool in the drive to not only increase awareness about 2Ds but also driving caregivers' to avail treatment whose children have been confirmed to have a defect or a developmental delay. It can be used extensively for follow-up, especially after caregivers realize that their child is screened to have any of the 2Ds. Frontline workers, community leaders, volunteers and social networks, including religious groups, GP members, mothers groups' and community gatherings can promote the key message of RBSK i.e. "to intervene early in the life of children born with birth defects and developmental delays to minimize future disabilities".

Since IPC is a very powerful medium to influence and motivate caregivers to get their child screened under RBSK and avail further treatment, following can be done to strengthen the IPC skills of FLWs/other community members/teachers:

FLWs

- IPC tools for use by ASHAs and ANMs to understand visible birth defects, and to explain RBSK, importance of screening, etc. Screening kits for ASHAs to conduct home-based newborns screening
- Pictorial toolkits and job aids for each Mobile Health Team to ensure they can explain different conditions
- Contact information of key personnel of RBSK at Block and District level (MHTs, RBSK coordinator, etc.)
- Information on various government health insurance schemes available in the state, especially for the poor and marginalized communities

Other Community members

- Capacity building of GP, SDMC, and SHG members and other community leaders to facilitate dialogues in their communities about RBSK and importance of early intervention for children with 2Ds

Teachers

- Timely information on the RBSK screening schedule
- Aids on RBSK like pictorial leaflets, guides, etc. to assist her during IPC and counselling of caregivers
- Contact information of key personnel of RBSK at Block and District level (MHTs, RBSK coordinator, etc.)
- Information on various government health insurance schemes available in the state, especially for the poor and marginalized communities

Mid-media and folk-media

According to the context, the stakeholders and the resources available, a mix of different media can be used to sensitize on the key aspects of the RBSK and promote key behaviours especially among the caregivers of the children. The communication medium can range from the more common ones, such as hoardings and wall paintings, as well as traditional ones, including folk arts and theatre and can be used as reinforcement to IPC and mass media activities. Combining different media to disseminate same messages related to key behaviour also promotes effective behaviour change. These mediums can be used to reinforce the key messages among the caregivers of the children in the age group 0-18 years. An attempt can be made to make these as pictorial as possible so that even uneducated/ semi-literate parents in rural areas can understand. An integrated approach can be used to ensure that all the messages related to health seeking behaviour are consistent and reinforce each other. Some of the initiatives that can be taken under this category are listed below:

Poster/Hoardings/Wall paintings:

- Posters on development milestones displayed in all public health facilities
- Posters on continuum of care of RBSK from screening, to referral to evaluation and management displayed in the waiting area at health facility
- Display RBSK posters/wall paintings with information on various 2Ds, screening to treatment process and messages on 'cure vis-a-vis care' at Panchayat office, AWCs, School Building complex, etc.
- Flex boards/ poster with time and date of screening is displayed outside the Anganwadi Center or School where the screening is planned

RBSK-specific display area/corner can be created in each PHC/CHC/DH/DEIC where information like government health insurance schemes, RBSK success stories, contact information for higher centres for evaluation and management of 2Ds, list of key hospitals and services offered in the district and nearby districts, contact information of District/Block level RBSK staff, etc. can be displayed

Child Health Screening Card could potentially have a page of pictorial information on developmental milestones and RBSK continuum of care citing the importance of RBSK

Public Service Announcements (PSAs) to popularize screening date/venue at all popular spots including weekly bazaars, markets, etc.

Mass-media

Mass media can reach large audiences cost-effectively through the formats of radio, television and newspapers. Mass media campaigns that follow the principles of effective campaign design and are well-executed can have small to moderate effect size not only on health knowledge, beliefs, and attitudes, but on behaviours as well. Mass media can have a major public health impact given its wide reach.

Since findings from the study indicated that nearly 45% of the respondents watch TV and it's a popular communication medium in rural areas, following can be done to increase awareness about the 2Ds and RBSK among the caregivers and the other community members:

- TV campaign with messages on normalizing disability and importance of early intervention for developmental delays and concept of 'rehabilitative care' into existing popular TV serials
- Creating TV spots on RBSK on local cable and satellite and provide RBSK related important information like screening schedules, evaluation camps, etc.
- Positive role model short film (3-4 minutes) and hosting talk shows with role models such as Paralympic winners/participants to create a positive attitude towards disability among communities
- CDs with AV running at District hospitals/SNCUs/CHCs/PHCs on developmental milestones to be showcased when pregnant women come for ANC/PNC check-up

Information and Communication Technology (ICT) / Mobile Technology

ICT is the fastest growing and evolving approach, with an increasing ownership and usage¹⁶ of mobile phones in rural India. ICT can be used effectively to disseminate highly tailored messages to the intended audience while also receiving feedback from them and encouraging real-time conversations, combining mass communication and interpersonal interaction.

Some of the initiatives that should be taken under this category are listed below:

- Leverage existing toll-free helpline such as women's helpline (1091) or set-up new toll-free helpline where mothers/caregivers can receive emotional support and strength, and information on coping with caregiver stress and information on different conditions, answer evaluation and treatment related queries of the caregivers of the children confirmed to have 2Ds
- Sending updates/reminders for the next steps of the treatment/evaluation of the child through text messages/SMS and/or Interactive Voice Response (IVR)

Specific information on communication approaches to be used are described in greater detail in the communication plan in the next Chapter.

¹⁶ 81% of respondents in the formative study reported using a mobile phone

How to Implement the National Communication Framework for RBSK

This Framework is a guidance document to support the advocacy and communication interventions at national and state level in achieving RBSK goals. It envisages achieving the advocacy and communication objectives in a phased manner:

Phase 1: Raising awareness for promoting SBCC among caregivers, their families and communities including IPC

Phase 2: Advocacy for creating an Enabling Environment

The two phases to achieve the supply and demand-side objectives are not sequential and there will be a degree of overlap in activities carried out during implementation. While the national level maybe coordinating advocacy for creating an enabling environment, the states can focus on developing contextualised communication materials for promoting SBCC among caregivers, their families and their communities.

Setting Priorities for Communication Framework

The Communication Framework is comprehensive and focuses on a variety of SBCC approaches, and advocacy, each State should customise communication needs, and materials based on their local context. Based on findings with respect to communication needs of caregivers, following have been prioritized:

- Interpersonal Communication (IPC) for Caregivers
- Advocacy with National and State Officials for creating impetus for RBSK

Phase 1: Raising awareness for promoting SBCC among caregivers, their families and communities

This approach would focus on using various means of communication to reach caregivers, their families and communities both directly through interpersonal/social contact and indirectly through mass and mid-media in order to help change knowledge, attitudes, beliefs, mind sets, perceptions and practices. Some of the key interventions in this approach would be:

1. **IPC^{17*}**: Since FLWs are a trusted source of health related information in the community, IPC pictorial toolkits would be helpful for them to understand visible birth defects and to explain RBSK, and importance of early screening to caregivers. In addition, pictorial toolkits and job aids for MHTs will help them to explain different conditions to the caregivers of children screened to have 2Ds.

¹⁷ * Indicates Prioritized Communication Activity

2. **Role models:** Role models add credibility as well as visibility to any programme. Engagement of role models (Paralympics athletes) to promote key behaviours would help normalize disability as well as raise the visibility and popularity of RBSK.
3. **RBSK kiosks in government health facilities:** It was observed during the study that, many caregivers felt lost at the health facility in the absence of any single contact point. Hence, creating small kiosks at these facilities would be helpful to facilitate such caregivers in navigating through the system and get the necessary evaluation/treatment done for the child.
4. **Helpline:** Since caregivers (especially mothers) of the children having 2Ds has to be under constant stress of raising such child, a helpline is useful to answer their queries related to evaluation and treatment of the child.
5. **Mid Media:** These will support inter-personal communication and give credibility to community level communicators as well create an enabling environment.
6. **Mass Media:** Television spots will be helpful to address knowledge gaps, enhance self-efficacy, promote positive behaviours and increase awareness about RBSK among caregivers. Further, Publishing RBSK success stories in the local newspapers and popular magazines will help in spreading positive word about RBSK.
7. **Community Mobilization:** Existing platforms such as VHNDs and other SHGs like mother support groups can be used to sensitize community on the importance of early screening of children to prevent possible future disabilities.
8. **ICT/Mobile:** SMSs/Voice SMSs and outdoor activities in partnership with cellular companies would be an effective means of reaching out to caregivers at scale.

Detailed Social and Behaviour Change Communication Plan for Screening under RBSK

Barriers	Desired Behaviour for Primary Caregivers	Desired Behaviours for Secondary Audience	Communication Channels	Sample indicators	M&E
		Family	Community	Health System	
Difficulty in carrying older children (4-18 years) with physical disabilities including conditions such as neural tube defect	Screening at AWC/School Parents/caregivers know major development milestones for infants (0-1 year of age)	Family members encourage parents of children to go for screening of their child	Community members share positive experiences about the health system/Providers especially parents who may have benefitted from RBSK earlier	FLWs and teachers communicate timely information regarding the screening date and venue to the parents	IPC* IPC pictorial booklets for use by ASHAs to understand visible birth defects, and to explain RBSK, importance of screening, etc. Screening kits for ASHAs to conduct home-based newborn screening
Time lost by caregivers while waiting for their turn for screening of their child	Caregivers know of their right to avail screening services and take their children for screening services	Family members help in carrying child to the screening site, if parents are not available	Support groups for mothers/caregivers to alleviate caregiver stress	AWWs/ASHAs facilitate parents in bringing their child to the screening site	# of parents aware of RBSK details # of schools/ AWCs with poster on RBSK continuum of care
Many caregivers don't have correct / complete information about screening	Caregivers are aware and understand the concept of screening, and early intervention for children	Family members manage household activities, while the caregivers accompany their child for screening	Informal health providers (IPs) guide parents/caregivers to seek medical help when they identify children with 2Ds	Capacity Building of ASHAs and MHTs to counsel mothers of children with 2Ds to guide them towards where, how to get evaluation and treatment	# of parents aware of developmental milestones of children 0-2 years
Many caregivers do not have faith in the public health system / providers because of their past experiences	Caregivers clarify any doubts regarding RBSK or screening			MHTs fill up the Health Card for all children and leave a copy with parents and school for future record-keeping	# short films aired on Paralympic role model
Many parents are fed-up that screening is not helping	Caregivers are			Capacity building of Informal Providers (IPs) to counsel caregivers of children with 2Ds to seek medical help	# TV shows aired for motivating parents to come forward for screening
				Capacity building of PRIs, SDMCs, and SHG	

Barriers	Desired Behaviour for Primary Caregivers	Desired Behaviours for Secondary Audience	Communication Channels	Sample indicators	M&E
	present at the time of screening to be able to understand their child's condition and intervention required	If the child is screened to have any of the 4Ds, MHTs explain the condition of the child to the parents using a pictorial toolkit	members and other community leaders to facilitate dialogues in their communities about RBSK and importance of early intervention for children with 2Ds. To also create support groups to help the family in availing care		
	Caregivers maintain the Child Health Screening Card given by the MHT for future follow-up visits	Educate/counsel caregivers on the next steps to be taken for further evaluation and management of the condition	Mid Media Posters on key development milestones in all public health facilities / delivery points/ SNCUs		
	Caregivers know where and when to go for follow-up after screening is complete		Posters on the continuum of care of RBSK from screening, to referral to evaluation		
	Mother and father of the child concerned decide about taking their child for further referral and evaluation	Home-based screening ASHAs conduct new born screening for all children in age group 0-6 weeks by visiting their homes	displayed in the waiting area at all health facilities (incl. SNCUs), schools, and AWCs		
	Screening at home Parents are available at home	ASHAs refer children screened to	Child Health Screening Card to have pictorial information on developmental milestones and about RBSK continuum of care Wall-painting Board/poster with screening time		

Barriers	Desired Behaviour for Primary Caregivers	Desired Behaviours for Secondary Audience	Communication Channels	Sample indicators	M&E
	when ASHAs come to their house for newborn screening	have any of the 2Ds to the nearest PHC/CHC or ANM	and date displayed outside the AWCs and Schools, and popular areas (kirana shops/ GP offices)		
	Parents understand the importance of newborn screening	ANMs should further check the child's condition and refer the child to a higher center for evaluation and treatment	Public Announcements (PSAs) for popularizing screen day		
	<u>Screening at Delivery Points</u> Parents spend at least 48 hours at the Delivery Point so that the child can be examined for any visible birth defects	<u>Screening at Delivery Points</u> For screening at delivery points, providers at PHCs/CHCs/ DHs screen all children born for all RBSK conditions across all the delivery points before discharging the family and refer children with any condition for	Contact information of RBSK Coordinator at District / Block / MHTs to be displayed at GP offices / Schools/ AWCs		
	Parents understand the importance of newborn screening		Wall paintings / Posters on government health insurance programmes at all public health facilities		
	Parents of children who were treated in SNCUs conduct follow-up visits to the health facility at least once a month until the child is about		<u>Mass Media:</u> TV campaign with messages on normalizing disability and importance of early intervention for developmental delays and concept of 'rehabilitative care' into existing popular TV serials Hosting talk shows with role models such as Paralympic winners/		

Barriers	Desired Behaviour for Primary Caregivers	Desired Behaviours for Secondary Audience	Communication Channels	Sample indicators	M&E
	one year old	<p>further evaluation and check-up</p> <p>For all children admitted in SNCUs, providers screen the children for any potential birth defects or developmental delays, and follow-up once a month</p>	<p>participants</p> <p>CDs with AV running at District hospital/PHC/CHC on developmental milestones to be showcased when women come for ANC/PNC check-up</p> <p>Positive role model short film (3-4 minutes) showing a Paralympic¹⁸ athlete with their sport to educate and give hope to parents of children with 2Ds</p> <p>Use local newspapers to have stories on importance of early intervention for children born with birth defects and developmental delays</p> <p>Publish success stories of children who obtained free treatment in the local newspapers / magazines</p> <p><u>Community Mobilization</u> Use existing platforms</p>		

¹⁸ *Athlete Girisha HN, who has a club foot, won a silver medal in high jump at the London Paralympics in 2012*

Barriers	Desired Behaviour for Primary Caregivers	Desired Behaviours for Secondary Audience	Communication Channels	Sample indicators	M&E
		Family	Community	Health System	
			such as VHNDs to educate and sensitize community on disabilities, causes, and ways to prevent 2Ds		
			Create mothers support groups in each GP (led by community volunteers)		
			<u>ICT/Mobile</u>		
			Leverage existing toll-free helpline on lines of Vanitha Sahayvani (1091) where mothers/caregivers can seek emotional support and strength, and information on coping with caregiver stress		

Communication Plan for Evaluation and Management¹⁹

Barriers	Desired Behaviours for Primary Caregivers	Desired Behaviours for Secondary Audience	Communication Channels	Sample M&E indicators
	Family	Community	Health System	
Out-of-pocket expenses for diagnostics, accommodation, etc. incurred by the caregivers while accessing care for their child with 2Ds in the government health facility	Caregivers understand the prognosis made by MHTs Caregivers maintain the referral related documents (Child Health Screening Card) and seek information from MHTs	Family members encourage caregivers of child screened with the 2Ds to go for further evaluation of the child as referred by MHTs	Frontline Workers ASHAs to provide necessary information to the caregivers of the children in the age group 0-6w for further evaluation of the conditions as identified by them during the home based screening	IPC* ASHAs and other FLWs to use pictorial booklets on RBSK for IPC and counselling to the caregivers of the children affected with 2Ds # of children evaluated to have a 2D availing successful treatment at public health facility
Recurring expenses for drugs for certain conditions (e.g., neurological impairment)	Caregivers visit the PHC/CHC/DH/DEIC/camp for further evaluation of the child, as directed by MHTs within the stipulated time period	Community members organize loans with support from GP members to help caregivers with basic expenses such as transportation, food, accommodation, etc.	Having a specific RBSK Kiosk/Helpdesk at the facility (PHC/CHC/DH/DEIC) on the day of the evaluation to receive all caregivers ASHAs/AWWs counsel and motivate the caregivers to take necessary steps required for further evaluation and management of their child ASHAs/AWWs provide information to the caregivers on various government health insurance schemes, which can help them to fund the	# of facilities with specific RBSK kiosks/ Helpdesks to help pictorial caregivers booklets to explain the different RBSK conditions and type of care and treatment options to the caregivers # of RBSK ads aired on TV # FLWs
Wage loss experienced by caregivers due to repetitive trips made by them to the health facility for evaluation/ treatment/ management of their child	Caregivers consult the specialist at the referral facility for the evaluation of the child to confirm the prognosis made by MHTs Caregivers get necessary diagnostic tests for the child as suggested by the specialist	Caregivers offer transportation, etc.) to the referral health facility for evaluation/ management of the child Family members manage other household	DEIC staff / MOs to use pictorial booklets to explain the different RBSK conditions and type of care and treatment options to the caregivers	
Transportation cost faced by caregivers in	For caregivers of children confirmed to			

¹⁹ Many of the communication channels mentioned under screening will also be relevant under evaluation and management. Duplication may be avoided where feasible

Barriers	Desired Behaviours for Primary Caregivers	Desired Behaviours for Secondary Audience	Communication Channels	Sample M&E indicators
	Primary Caregivers	Family	Community	Health System
carrying child to the referred health facility	have 2Ds: Caregivers take the child to the referred higher center for the further treatment/care of the child	things, while the caregivers are out for evaluation/management of the child	Communities form mothers' groups' with children with 2Ds so that the network can provide emotional support	DEIC/DH staff to counsel caregivers on serious surgical procedures (for conditions such as CHDs, Club foot, Neural Tube Defect) to trained RBSK
Long waiting time for evaluation/ treatment/ management of child in the health facility experienced by caregivers	Caregivers visit the higher center for follow-up care and therapy of the child, if repeat follow-ups are required	When possible, family members provide monetary support to the caregivers for evaluation/treatment of the child	ANMs refer children with 2Ds for further evaluation	# SNCU graduates followed-up by a health provider at least once a month
Cost burden of long-term care that may not be covered by RBSK is a major barrier for most families	Caregivers ensure child receives all therapy/care/medicines at home and follow instructions received at DEIC/DH (especially for children with speech impairment, hearing impairment, neuro-motor delay, etc.)	Family members provide emotional support to alleviate caregivers' stress	Facility-Level Receive the caregivers with children screened to have 2Ds with care and empathy	Providers to counsel parents of children who were admitted in SNCUs about the need for regular check-up / follow-up
Limited attention from health providers when families reach health facility as providers are not oriented on RBSK and conditions covered under it and due to heavy caseload at public health facilities	Caregivers with positive experiences share about benefits of RBSK with community members / neighbors		Mid Media Health providers to assist caregivers at the health facility by helping them in navigating through the health system by filling out forms, guiding them towards specialist, diagnosis facility, etc.	Display posters with information on 2Ds, continuum of care of RBSK, and messages on cure vs care at Panchayat office, AWCs, School Building, etc.
Caregivers often do not possess information about other health programmes (insurance programmes) that can provide financial support	Caregivers support other parents and guide them on how RBSK works and spread the importance of early intervention		Provide quality care during the treatment/management by explaining the condition of the child to the caregivers	Create RBSK-specific display area/corner to be created in each PHC/CHC/DH/DEIC where information

Barriers	Desired Behaviours for Secondary Audience			Communication Channels	Sample M&E indicators
	Primary Caregivers	Family	Community	Health System	
Caregivers feel the need to have 'guarantee' that their child's future will be healthy after the surgery/ treatment				Counsel caregivers for any fear related to surgery Ensure that the caregivers do not face any difficulty in getting medicines for their children undergoing treatment/management	including government health insurance schemes, RBSK success stories, contact information for higher centers for evaluation and management of 2Ds, contact information of District/Block level RBSK staff, etc. can be displayed
In tribal pockets of North East, parents also do not trust the medical system due to trust in their local informal providers				DEIC staff/providers to explain physical exercises, therapy for parents to practice at home with their children	Mass Media: Short TV ads on RBSK with positive role models e.g. athletes from para Olympics, etc. Publishing RBSK success stories in the local newspapers
Caregivers perceive medicine to be curative and cannot distinguish between 'care' and 'cure'				DEIC staff conduct follow-up calls to parents for repeat visits for 'rehabilitative care / therapy' sessions	Community Mobilization Create mothers support groups in each GP (led by community volunteers and mothers of children
Caregivers do not understand the concept of management of certain conditions such as developmental delays (rehabilitative care)					
In the absence of understanding of rehabilitative care, caregivers tend to give					

Barriers	Desired Behaviours for Primary Caregivers	Desired Behaviours for Family	Desired Behaviours for Community	Desired Behaviours for Secondary Audience	Communication Channels	Sample M&E indicators
<p>up on medical care in the absence of any 'cure'</p> <p>Caregivers in certain cases, may require multiple referrals to different health facilities for evaluation/treatment of their child causing transportation, wage loss, and other concerns</p> <p>Many caregivers have a fatalistic attitude towards the 2Ds</p> <p>In the absence of proper information, many caregivers have certain fears with associated medical procedures like surgery, etc.</p> <p>Caregivers experience fatigue and stress as the child may only have limited improvements even after spending money on travel, and</p>					<p>with 2Ds</p> <p>ICT/Mobile: Helpline to answer evaluation and treatment related queries of the caregivers of the children confirmed to have 2Ds</p> <p>Sending updates/reminders for the next steps of the treatment/evaluation of the child through text messages/SMS</p>	

Barriers	Desired Behaviours for Primary Caregivers	Desired Behaviours for Family	Desired Behaviours for Secondary Audience	Communication Channels	Sample M&E indicators
experiencing loss	wage				

Potential Funding

Indicative sources of funding from Programme Implementation Plan (PIP) includes for SBCC activities include: RBSK IEC budget (FMR code B.10.7)

Phase 2: Advocacy^{*20} for creating an Enabling Environment

Since RBSK is of national importance, the implementation of this communication framework will be led by the MoHFW as the convening Ministry and at the State level by the respective Departments of Health and Family Welfare. The Communication Framework envisages inter-ministerial and intra-departmental convergence with the existing programmes of the MoHFW and other ministries. Currently, there are other ministries that address issues of CWSNs. Prominent among them are Ministry of Human Resource Development (MHRD), Ministry of Women and Child Development (MWCD) and Ministry of Social Justice and Empowerment (MSJE). The efforts would need to be expanded to include celebrities, NGOs, civil society organizations, media, IT and Telecom companies and the private sector.

Advocacy with these various stakeholders will play a key role in ensuring that there is a supportive policy and programme environment in which the communication framework can be effectively implemented. Some of the key interventions in this approach would be:

1. **Orientation workshops on RBSK:** These workshops would be needed to sensitize health and other department officials about the importance of screening and minimizing disabilities for a healthy future of India. Further, they will help in increasing the scope of convergence with Ministries and national flagship.
2. **National-level Consultations with all state Chief Ministers, Ministers and Secretaries:** Sensitization workshops/meetings with senior representatives from stake holding ministries/departments at national level would need to be held to get their buy-in and support.
3. **State-level Consultations with RBSK State Officials, State Representatives from Other Departments, Elected Representatives of ZP:** Orientation workshops/meetings with senior representatives from RBSK, Health, WCD, Education, Disability to get their buy-in and support to strengthen implementation of RBSK
4. **District/Block level meetings between health and other department officials:** One-to-one meetings between representatives of ICDS, Education, CS/CMO, DC/DM and ZP members at a defined frequency(monthly/quarterly) will help in ascertain progress of RBSK in the district convergence related issues

Implementation Framework is appended in Annex 1: Suggested Implementation Framework

²⁰ *Indicates Prioritized Communication Activity

Capacity Development

Need for Capacity Development

This chapter summarizes the various capacity development measures required at departmental (State/District/Block) as well as individual levels to ensure effective implementation of the RBSK communication plan. As described in the situation analysis earlier, in the absence of an effective communication plan, the knowledge among beneficiaries and other programme delivery functionaries at State/ District/ Block/ Community levels about RBSK is quite poor. This contributes to low utilization of RBSK services, especially the evaluation and management of screened cases. Many of the health functionaries also do not possess the capacity to implement overarching guidance including setting-up MoUs with private sector, religious trust hospitals, non-profits, etc.

Since the programme is in its infancy, it is the right time to introduce capacity development measures for the supply side functionaries of RBSK.

Building Internal Capacity of Health System

In order to increase effective utilisation of RBSK and to provide assistance to the caregivers of the children screened to have 2Ds, several capacity development measures are required within the health system at State/District/Block level. Some of the key measures required are mentioned below:

1. **Training of Health officials:** Training/Sensitizing health officials at DH/PHC/CHC about RBSK will help them to understand the details of the programme, which will help them to attend caregivers visiting health facilities in a better way.
2. **Mapping of health services at State/District level:** This will enable health officials to refer RBSK patients in an efficient manner. Additionally, it will help caregivers to navigate through health system easily.
3. **MoUs and partnerships with NGOs, Trusts and Private sector:** Since treatment of many 2Ds covered under RBSK is expensive, and limited capacity is available with government health system to handle such patients (especially in the absence of DEICs). Building capacity at State/District level to develop such partnerships is crucial for the success of the programme.
4. **Development of IPC tools for FLWs:** Since FLWs are a trusted source for health related information in the community, IPC tools like pictorial booklets, etc. are to be developed and distributed among them, to empower them in counselling caregivers of children having 2Ds.

Suggested Capacity Development Measures

In the context of the training related gaps identified in the Formative Research Report, several capacity development measures are required for different levels of stakeholders. The funding for this required

capacity development can predominantly come from the RBSK training budget, which is under-utilised in most states. These capacity development needs are summarised in the table below.

Table 2: Capacity Development Needs by Type of Stakeholder

Stakeholder		Capacity Development Needs	Budgets
State	Health Officials	<ul style="list-style-type: none"> Training to understand RBSK's objectives clearly and their roles in programme implementation Conduct a training needs assessment to understand gaps that may exist across district, block and community level to roll-out trainings for them Capacity to develop State Training Plan with a list of people to be trained/sensitized and develop tailor-made training plan for both Officials in Health Department and other related Departments, MHTs, and FLWs Develop the ability to advocate and influence policy makers, decision-makers with relevant information to motivate them to take action on critical issues related to availability of RBSK infrastructure (DEICs) to improve utilization Ability to develop MoUs for appropriate partnerships with hospitals and funding organisations to provide treatment and management of the 2Ds Ability to connect with non-profit organization and civil society organizations who can assist with funding tertiary care for BPL families Ability to map key service providers offering tertiary care and management services across their state Advocate for convergent platforms with other relevant Ministries/ Departments Understand the importance of IEC for the programme and what IEC/ BCC encompasses Training to make effective convergence mechanisms with other departments 	RBSK training budget (FMR code A.9.12)
	District Health officials	<ul style="list-style-type: none"> Training to understand RBSK's objectives clearly and their roles in programme implementation Importance of IEC for the programme and what IEC/ BCC encompasses Ensuring effective implementation of IEC/ BCC activities Ability to sensitize frontline workers are appropriately sensitised/ oriented towards the programme Ability to train MHTs and FLWs on the programme, and clarify any doubts Ensuring effective convergence mechanisms with other departments (for example, by setting up a district level committee or leveraging DC/DM meetings) Ability to map key service providers offering tertiary care and management services across their state 	RBSK training budget (FMR code A.9.12)

Stakeholder	Capacity Development Needs	Budgets	
	<ul style="list-style-type: none"> Ability to connect with non-profit organization and civil society organizations who can assist with funding tertiary care for BPL families 		
Block Health officials	<ul style="list-style-type: none"> Training to understand RBSK's objectives clearly and their roles in programme implementation Importance of IEC for the programme and what IEC/ BCC encompasses Ensure that frontline workers and teachers are appropriately sensitised/ oriented towards the programme Training to institutionalize recognition rewards for MHTs/ FLWs motivated and performing well in the programme Ensuring adherence to convergence mechanisms with other departments 	RBSK budget	training (FMR code A.9.12)
IEC officials	<ul style="list-style-type: none"> At the National-level, training to develop IPC tools for ASHAs or leverage the modules developed by UNICEF (TARANG SBCC Training Module) At the State-level, training to understand IEC/BCC approaches available At the State-level, training to customise locally contextualized IPC tools for ASHAs Capacity to develop culturally appropriate IEC/ BCC materials taking into consideration state and local context; Capacity to monitor that district and block levels disseminate IEC materials and ensure that they are adequately used 	RBSK budget	IEC (FMR code B.10.7)
Other Departments	<ul style="list-style-type: none"> Sensitisation on the programme, its objectives and why it is important/ beneficial Understanding the importance of the role played by teachers/ AWWs Understanding the importance of adherence to convergence mechanisms set up by Health officials Supporting the Health Department by encouraging mobilisation of children for screening 	Not Available	
Mobile Health Teams	<ul style="list-style-type: none"> Refresher training on conditions and their complexities (every year) Interpersonal communication and soft skills training on how to communicate with caregivers (every year) Multi-skilling to provide empathy, guidance and counselling to parents of children with 2Ds Increasing self-motivation and involvement in the programme to encourage follow-ups with parents Develop ability to advocate for greater focus on the programme at block/ district level, among health and other department officials 	RBSK budget	training (FMR code A.9.12)
Frontline Workers	<ul style="list-style-type: none"> Sensitisation on the programme, its objectives and why it is important/ beneficial 	RBSK budget	training (FMR)

Stakeholder	Capacity Development Needs	Budgets
Teachers	<ul style="list-style-type: none">▪ Interpersonal communication and soft skills training to explain the programme to the community, encourage utilisation, counsel caregivers and mobilise effectively▪ Increase self-motivation/ involvement in the programme and highlight the importance of their role to serve as a means of incentivising performance	code A.9.12)

Annex 1: Suggested Implementation Framework

Implementation comprises of the concrete measures that translate a Framework into actions that can produce results. Given that this Communication Framework feeds into RBSK, one of the key programmes within National Health Mission, implementation is the key link between Framework and the action plans that are executed by programme staff to achieve the desired behaviour change.

Implementation necessitates understanding of the Health Departments at National, State, District, Block and Village levels, and examination of inputs required to operationalise the Communication Framework.

The details on the implementation steps at each level are presented below:

National Level: Advocacy Activities

Stakeholders	Advocacy Activities	Inputs required	Support Partners
<ul style="list-style-type: none">Decision Makers/ Policy makers of RBSK at MoHFW	<ul style="list-style-type: none">Orientation workshops on RBSK highlighting the following:	<ul style="list-style-type: none">Develop standard framework for conducting	<ul style="list-style-type: none">UNICEFDonorsPrivate sector

Stakeholders	Advocacy Activities	Inputs required	Support Partners
<ul style="list-style-type: none"> Representatives of Central IEC/BCC Bureau Representatives of convergence ministries Elected Representatives- Parliamentarians, Ministers (Union and State of the core and convergent Ministries) National representatives of UNICEF, other donor agencies, etc. 	<ul style="list-style-type: none"> Importance of screening and minimizing disabilities for a healthy future of India Information on other related programmes of national importance under different ministries e.g. IE-SSA, DDRC, etc. Increasing the scope of convergence with Ministries and national flagship- e.g. advocacy with MoSJE for co-locating DDRCs with DEICs, wherever required Development of standards and guidelines; direction and circulars/letters to state for improving implementation of the RBSK National Consultations with all Chief Ministers, Ministers and Secretaries handling the relevant Departments for enhanced collaboration/activities on effective utilization of RBSK 	<ul style="list-style-type: none"> workshops Develop evidence based advocacy package, covering <ul style="list-style-type: none"> Fact sheets on progress of RBSK on various defined parameters Presentations with programme related information short films of good practices around the country on RBSK E.g., Model DEIC video 	

State Level: Advocacy Activities

Stakeholders	Advocacy Activities	Inputs required	Support Partners
<ul style="list-style-type: none"> Decision Makers of RBSK at State level Representatives of State 	<ul style="list-style-type: none"> Orientation workshops on RBSK highlighting the following- <ul style="list-style-type: none"> The importance of screening and 	<ul style="list-style-type: none"> Develop standard framework for conducting workshops 	<ul style="list-style-type: none"> UNICEF Donors Private sector

Stakeholders	Advocacy Activities	Inputs required	Support Partners
IEC/BCC Bureau <ul style="list-style-type: none"> State representatives of convergence ministries(MoHFW, ICDS-WCD, DoE-MHRD, MoSJE) Elected representatives - MLC,MLA, Zila Parishad District Magistrates/ District Collectors State representatives of UNICEF, other donor agencies etc. 	<ul style="list-style-type: none"> minimizing disabilities for a healthy future of India <ul style="list-style-type: none"> Information on other related programmes of national importance under different ministries e.g. IE-SSA, DDRC, etc. Information on current convergence and scope of convergence with key departments and national flagship programmes. E.g. advocacy with MoSJE for co-locating DDRCs with DEICs, wherever required Conference with DMs/DCs of all districts for prioritizing utilization of RBSK to minimize disabilities in the districts and hence the state, could also be a platform to share initiatives at district level; lessons learnt will inform and improve implementation of RBSK Field visits to best practice areas, where the utilization of RBSK is improved at a rapid rate in the recent past, advocacy of these best practices for other districts of the State 	<ul style="list-style-type: none"> Develop evidence based advocacy package, covering <ul style="list-style-type: none"> Fact sheets on progress of RBSK on various defined parameters Presentations with programme related information Short films of good practices across the state on RBSK E.g., Model DEIC video Identify locations and facilitate field visits 	

District Level: Advocacy Activities

Stakeholders	Advocacy Activities	Inputs required	Support Partners
<ul style="list-style-type: none"> RBSK district coordinator DHO and CS/CMO 	<ul style="list-style-type: none"> RBSK orientation workshops for members of education, nutrition, social welfare and other related 	<ul style="list-style-type: none"> Evidence based advocacy package in local language 	<ul style="list-style-type: none"> UNICEF Donors Private sector

<ul style="list-style-type: none"> • ICDS officer • DEO • District Magistrates/ District Collectors • ZP members • PRI bodies 	<ul style="list-style-type: none"> • departments • One-to-one meetings between representatives of ICDS, Education, CS/CMO, DC/DM and ZP members at a defined frequency(monthly/quarterly) to discuss <ul style="list-style-type: none"> ○ Progress of RBSK in the district ○ Convergence related issues • Field visits to better performing blocks (with respect to RBSK) 	<ul style="list-style-type: none"> • Fact sheets on RBSK
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National and State Level: Communication Activities

Communication Activities	Inputs required	Support Partners
<ul style="list-style-type: none"> • Role model outreach campaign <ul style="list-style-type: none"> ○ Engage a role model (Paralympics athlete) to promote key behaviours. These can be popular figures at national, state/regional level ○ Develop short films with role model to normalize disability for mass media ○ Involve role models to give away awards to best performing MHTs and other RBSK officials • Mass media campaign <ul style="list-style-type: none"> ○ TV, Print, Online media (Hindi and regional/local languages) ○ RBSK specific AV content for Health facilities 	<ul style="list-style-type: none"> • Identify role models to champion the cause /select brand ambassadors • Develop appeals with role models/ brand ambassador for screening and early intervention under RBSK • Organize events like “RBSK day”, celebrities to distribute awards on this day • Content creation for messaging on the select behaviours for different mediums including video appeals, print advertisements, press releases, SMS/text • Hosting talk shows with role models such as 	<ul style="list-style-type: none"> • UNICEF • Donors • Ministry of Information and Broadcasting (MIB) • Ministry of Information Technology and Telecommunications • Private sector

Communication Activities	Inputs required	Support Partners
Efforts should be made to synergize the broadcast at national and state level.	<ul style="list-style-type: none"> Paralympic winners/ participants Detailed media plan for the dissemination of messages for every medium- this should include <ul style="list-style-type: none"> Specific timelines Selection of TV channels and print based on credible ratings Time of exposure to target certain audiences- for example placement of ads/short films at prime time- between popular soap operas, or before and after news on popular news channels Embedded messages through popular serials on TV Embedded messages in feature films or documentaries developed on the issue (such as Taare Zameen Par on issue of learning disability) 	
Mobile campaign	<ul style="list-style-type: none"> Develop creative content/RBSK related messages/reminders to be disseminated through mobile phones via SMS or IVR Alliance with mobile telephony service providers 	<ul style="list-style-type: none"> UNICEF Ministry of Information and Broadcasting (MIB) Ministry of Information Technology and Telecommunications Private Sector
<ul style="list-style-type: none"> Partnership can be forged with a service provider for initiating <ul style="list-style-type: none"> SMS campaign IVR campaign Mobile messages through bulk SMS/music/jingle/ caller tunes Other innovative mobile messaging 		

District Level: Communication Activities

Communication Activities	Inputs required	Support Partners
<ul style="list-style-type: none"> RBSK hoardings at strategic sites Posters on key development milestones in all public health facilities / delivery points/ SNCUs Public Service Announcements (PSAs) for popularizing screening event Wall paintings / Posters on government health insurance programmes at all public health facilities Publish success stories of children who obtained free treatment in the local newspapers / magazines IPC job aids for FLWs 	<ul style="list-style-type: none"> Develop RBSK specific creative content for outdoor media and IEC materials Identification/mapping of sites- Health centres/ hospitals schools, etc. Select newspapers/magazines to publish RBSK success stories 	<ul style="list-style-type: none"> RBSK District coordinator District IEC Bureau UNICEF Consultants Private agencies

Block Level: Communication Activities

Communication Activities	Inputs required	Support Partners
<ul style="list-style-type: none"> RBSK hoardings at strategic sites Posters on key development milestones in all public health facilities / delivery points/ SNCUs Posters on the continuum of care of RBSK from 	<ul style="list-style-type: none"> Identification/mapping of sites- Panchayat Office, Health Centres/ Hospitals, Schools, etc. Arrange logistics for wall paintings, 	<ul style="list-style-type: none"> RBSK Block level coordinator Private agencies

Communication Activities	Inputs required	Support Partners
<p>screening, to referral to evaluation displayed in the waiting area at all health facilities (incl. SNCUs), schools, and AWCs</p> <ul style="list-style-type: none"> Public Service Announcements (PSAs) for popularizing screen day Wall paintings / Posters on government health insurance programmes at all public health facilities RBSK related information (like screening schedules, etc.) on local cable TV channels 	<p>hoardings, posters, etc.</p>	

Gram Panchayat Level: Communication Activities

Communication Activities	Inputs required	Support Partners
<ul style="list-style-type: none"> RBSK Screening schedules and evaluation camp schedule posters at AWCs and Schools Wall paintings at prominent locations like panchayat office, school premises, etc. 	<ul style="list-style-type: none"> Arrange logistics for wall paintings, posters, etc. at schools, AWCs, Panchayat Office 	<ul style="list-style-type: none"> RBSK Block level coordinator Teachers / MHRD GP members

Suggested timelines to implement sample Advocacy and Communication related activities at National/State/District/Block/GP level:

Year	1	2	3	4	5
<ul style="list-style-type: none"> Orientation workshops on RBSK to highlight importance of screening and a focus on minimizing disabilities among children in India 					
<ul style="list-style-type: none"> Share information on other related programmes of national importance e.g. IE-SSA, DDRC, etc. 					
<ul style="list-style-type: none"> Increase the scope of convergence with other Ministries and related programmes of national importance 					
<ul style="list-style-type: none"> Develop standards and guidelines; direction and circulars/letters to States for improving implementation of the RBSK 					
<ul style="list-style-type: none"> National Consultations with all Chief Ministers, Ministers and Secretaries handling the relevant Departments for enhanced collaboration/ activities on effective utilization of RBSK 					

<ul style="list-style-type: none"> Conference with DMs/DCs of all districts for prioritizing utilization of RBSK to minimize disabilities in the districts and hence the state, could also be a platform to share initiatives at district level; lessons learnt will inform and improve implementation of RBSK 					
<ul style="list-style-type: none"> Field Visits to best practice areas, where the utilization of RBSK is improved at a rapid rate in the recent past, advocacy of these best practices for other districts of the State 					
<ul style="list-style-type: none"> Celebrity outreach campaign- Engage a celebrity (Paralympics athlete/Bollywood) to promote key behaviours 					
<ul style="list-style-type: none"> Mass media campaign- TV, Radio, Print, Online media (Hindi and regional/local languages) and RBSK specific AV content for Health facilities 					
<ul style="list-style-type: none"> Mobile Campaign- Partnership to be forged with a service provider to initiate SMS campaign, Mobile messages through bulk SMS/music/jingle/ caller tunes and Other innovative mobile messaging techniques 					
<ul style="list-style-type: none"> Placing of RBSK hoardings at strategic sites 					
<ul style="list-style-type: none"> Placing of posters on key development milestones in all public health facilities / delivery points/ SNCUs 					
<ul style="list-style-type: none"> Use of Public Service Announcements (PSAs) to popularize screening event 					
<ul style="list-style-type: none"> Wall paintings / Posters on government health insurance programmes at all public health facilities 					
<ul style="list-style-type: none"> Publish success stories of children who obtained free treatment in the local newspapers / magazines 					

• Provide IPC job aids for FLWs					
• Place posters on RBSK Screening schedules and evaluation camp schedule at AWCs and Schools					
• Wall paintings at prominent locations like Panchayat Office, school premises, etc.					



Short Term Activities (1-3 Years)



Long Term Activities (3-5 Years)