Providing Services for Indian Children With Developmental Delay and Disabilities in the Community: Rashtriya Bal Suraksha Karyakram

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Investment in Early Childhood Development (ECD) is essential for the progress of a nation. In 2013, the Rashtriya Bal Suraksha Karyakram (RBSK) was launched for community level screening, early identification and management of chronic diseases (birth defects, diseases, deficiencies, developmental delays and disabilities) from birth to 18 years. Health care is provided in District hospitals with Special Newborn Care Units, and District Early Intervention Centers (DEIC). Infants are screened at delivery points, or at home under the Home-Based New-born Care package. Pre-schoolers and school aged children are evaluated by mobile health teams using standardized tools in anganwadi centers and schools, respectively. Referrals are managed at higher centers. The DEIC uses an evidence based, trans-disciplinary, collaborative approach for delay/disability at zero expense.

Other initiatives disseminating awareness about healthy family practices promoting ECD during pregnancy and the first two years of life include: a booklet '*Journey of First 1000 days*'; an android App '*Ayushman Bhava*'; ECD call centers that provide individualized counselling related to queries; the LaQshya program that promotes mother-friendly labour; and a more illustrative 'Mother and Child Protection Card' that assists in developmental monitoring.

Till date, RBSK has developed two Nodal Collaborating Centers (the Kolkata centre has trained 852 personnel), 234 DEIC's, and 11,000 mobile health teams. Over 6 years (2014 -2020), cumulatively 45,64,31,984 children < 6 years have been screened, 13,95,618 delays / disabilities identified, and 3,04,300 children managed appropriately. The future holds further expansion, development of state-of-the-art specialized centers, collaborative research, and self-sustaining capacity building of multi-disciplinary personnel.

Keywords: *Community, Early childhood development, Monitoring, Screening, Surveillance.*

The 'Convention on the Rights of the Child' (1989) states that every child has the right to a standard of living that is adequate for physical, mental, spiritual, moral, and social development. More than 30 years later, the latest Lancet series on early child development (ECD) estimated that 250 million or 43% children under 5 years (U5) were missing their expected developmental potential due to inequities in healthcare, socio-economic conditions and learning opportunities, in addition to adverse biological and psychosocial factors that hamper physical, cognitive and psychological development [1].

The first five years of a child's life is characterized by rapid brain growth persisting from the foetal period. Hubel and Wiesel demonstrated the significance of this 'critical period' of brain development [2], by showing severe and/or permanent alteration of the brain secondary to exposure to abnormal or adverse experiences during foetal and early years of life. Positive and negative biological, psychosocial and environmental factors influence ECD irrespective of genetic make-up. Optimal ECD lays the foundation for academic, behavioural, socio-and emotional competencies of children with long-lasting impact into adulthood; determining educational, professional and economic potential. Therefore, it is the cumulative responsibility of the parents/caregivers, the community and the government to ensure that every child is nurtured and supported, according to their individual needs.

The motto of the Global Strategy for Women's, Children's and Adolescents' Health (2016-2030) 'Survive, Thrive, Transform', expounds the belief that not only should every child live beyond the age of five years, but their rearing environments should support their health and well-being, and enable them to realize their full developmental potential. The 2030 Sustainable Development Goals 4.2 calls for individual country action so as to '*By 2030, ensure that all girls and boys have access to quality early childhood development, care and pre-primary education so that they are ready for primary education*' [3].

Given that Lancet's estimate of vulnerable children U5 years escalated from 200 million to 250 million in just a decade

(2007-2017), it is imperative that every nation employs an effective strategy to reach this goal. Evidence confirms that investing in ECD is one of the most cost-effective ways to improve human capital, showcased by educational achievement and increased skills and capa-bilities, and ultimately measured by national productivity. A country investing in universal programs that support ECD can save up to double the gross domestic product, that would otherwise be spent on health. The cost of inaction is definitely higher than action i.e., planning, implementing and sustaining such a program. High-income countries (HIC) have been running ECD programs since years. In the last decade, many low- and middle-income countries (LMICs) have been triggered into action by these issues.

Magnitude of Burden of Developmental Delay/ Disability in India

Marked improvement in antenatal and perinatal care in the last two decades has reduced neonatal mortality significantly. However, this has paradoxically led to many neonatal survivors with higher risk of developmental delay/disability. Out of 27 million babies born annually, 3.6 million are preterm. They require specialized developmentally supportive care, surveillance, early recognition of developmental deviation and easy access to well-equipped early multidisciplinary intervention centers. Meticulous post-discharge longitudinal follow up is practiced in few Indian centers.

The 2011 Government of India population census was unique, because interviewers included the term ‘disability’ for the first time [4]. Disability was observed in 12.9 lakh 0-4 year old (5% total), 19.6 lakhs 5-9 year old (7% total) and 46.2 lakhs 10-19 year old (17% total) children [5]. This may not be very accurate due to lack of proper operational definitions being used for diagnosing disability. The community based multicentric INCLEN study of neurodevelopmental disorders in children, in which consensus clinical criteria were used demonstrated the following distribution: in 2-6-year-olds– 0.7% visual impairment (VI), 1.1% epilepsy, 2.1% neuromotor impairment including cerebral palsy (NMI-CP), 3.3% hearing impairment (HI), 1.6% speech and language disorders (SLD), 1% autism spectrum disorder (ASD), and 3.1% intellectual disability (ID). The magnitude was 0.6% VI, 2.2% epilepsy, 1.3% NMI-CP, 2.6% HI, 1.6% SLD, ASD, 5.2% ID, 1% attention deficit hyperactivity disorder and 1.6% learning disorder (LD) in 6 -9-year-old children [6].

Challenges in Providing Early Intervention Services in the Indian Scenario

Developing well-equipped and adequately staffed facilities that can provide and sustain service delivery, equally throughout the country, to such a vast number of children is a herculean task. Ideally, early intervention should be transdisciplinary i.e., all personnel and equipment required for high-quality evaluative and therapeutic services existing under one roof [7,8]. At present, there are very few centers in India that can provide such services. Though most medical colleges have departments involved in the management of disability within their premises (Pediatrics, Ear-Nose-Throat, Ophthalmology, Psychiatry, Physical Medicine Rehabilitation, Orthopedics, etc.), there are hidden barriers. Besides pediatricians, most medical professionals are not specifically trained to handle young children as patients, let alone those with special needs; certain impairments particularly vision and hearing may get missed due to lack of age-appropriate instruments, and availability of professionals from allied branches (optometrist, audiologist, clinical psychologist, occupational therapist, speech and language therapist and physiotherapist). Parents have to visit various service delivery points, without clear instructions or signages. There is minimal intra- or inter-departmental discussion or collaboration in formulating intervention plans. Advice given by different personnel are often not properly explained, conflicting, or confusing. Some paraprofessionals, may not be recognized by their competent registration authority, or lack hands on exposure during their professional training.

All these reasons contribute to delay in parents seeking medical attention. This situation is worsened by the lack of dedicated training of clinicians to recognize and manage children with special needs. It is not uncommon for such conditions to be missed, or inappropriate and insensitive counselling be given, that parents lose the will to proceed any further. This leads to the child not receiving early intervention, whence the prognosis is the most optimal. Delay in access to services translates to increase in the mental, physical and financial stress of a family caring for a child with special needs. In a country like India, with such vast urban-rural differentials, there is definitely a strong felt need for competent, easily accessible multi-disciplinary professionals available in a single setting who are willing to meet the needs of these children and their families, at no or minimal cost.

The Indian Solution: Rashtriya Bal Suraksha Karyakram

India’s alignment with the global commitment to promote, support and protect ECD led to the launching of the Rashtriya Bal Suraksha Karyakram (RBSK) in 2013. This program led by the Ministry of Health and Family Welfare (MoHFW), is also linked to the Ministries of Women and Child Development, Human Resource and Development and Social Justice and Empowerment, as well as the Department of Empowerment of Persons with Disabilities. Run by the National Health Mission (NHM), the RBSK program was envisioned to enable free universal child health screening and access to early intervention services across the country. The philosophy is ensuring that every child moves from mere 'survival' to 'healthy survival', and can access quality health care based on scientific evidence and equity.

Initially, the goals of RBSK included screening, early identification and trans-disciplinary management of chronic health conditions; Defects at birth, Diseases, Deficiencies and Developmental delays including disabilities (4 D's), and some optional conditions [7,8]. At the onset there were 30 conditions. Recently 7 new health conditions have been added; defects (microcephaly and macrocephaly), deficiencies (vitamin B complex deficiency and severe stunting), and diseases (childhood leprosy, childhood tuberculosis and childhood extra pulmonary tuberculosis). Most of these conditions have some common characteristics. They are commonly found in children, and if untreated they may lead to death or poor developmental outcomes. Early detection coupled with timely and appropriate management improves cognition and prevents progression into an acute emergency, or transforming into permanent disability. These have not been addressed comprehensively by earlier national programs where the focus was more on addressing acute health conditions and reducing childhood mortality. Programs like the blindness control program/ deafness control program have been mostly vertical with little inter-sectoral collaboration. It is envisioned that if RBSK is successfully implemented, it will minimize health care visits and hospitalization, reduce 'out of pocket' expenditure, and decrease school and work absenteeism, for the family.

Since its onset, RBSK has broadened its goals and scope beyond screening and early intervention. It has added many initiatives that disseminate awareness about health practices promoting and supporting ECD in the community, especially during pregnancy and the initial two years of life. These include: *i*) An illustrative, culturally contextual book "Journey of First 1000 days" that delivers simple, practical messages for sensitizing expectant mothers and families about preconception care, conception, practices during pregnancy supporting foetal growth (stress reduction, proper nutrition, interaction with the foetus), delivery (dos and don'ts) and child rearing practices aimed at improving physical, cognitive and social development; *ii*) An android mobile app 'Ayushman Bhava' designed to also display similar educational information; *iii*) Interactive call centers that address queries and counsel pregnant women; *iv*) Labour room Quality Improvement Initiative (LaQshya) that makes the birthing process and environment 'mother and baby friendly'. This includes promoting physiological labour (enhancing natural oxytocin flow and avoiding unnecessary induction), delayed cord clamping, early skin to skin contact, and promoting early breastfeeding; *v*) Home-Based New-born Care package; and; *vi*) Redesigning the 'Mother and Child Protection Card' to increase public awareness about maternal/child health services, enabling the monitoring of growth and development, recognition of any developmental deviation and ECD supportive home-based practices.

This article will focus primarily on sensitizing our readers about the services that are provided by RBSK for screening for developmental delay and disabilities and briefly touch upon the services that available for managing them.

RBSK Screening for Early Detection of Developmental Delay/Disability

RBSK aims at screening children from birth to 18 years, beneficiaries being babies born at home or in public health facilities, pre-school children belonging to rural areas/urban slums, and children enrolled in Government or Government aided schools. Facility born babies are screened by health personnel within 48 hours of birth. All babies are evaluated within 6 weeks of birth under the Home-Based New-born Care package. Those identified with birth defects are integrated with the Janani Shishu Suraksha Karyakaram for further management. Pre-school (6 weeks to 6 years) and school aged children (6 to 18 years) are screened by Mobile Health Teams (MHT) at Anganwadi centers (AWC) twice a year, and at school annually. Conditions included in developmental delay/disabilities are VI, HI, NMI, motor delay, cognitive delay, language delay, behavior disorder i.e., ASD, LD and ADHD.

The MHT is comprised of two trained AYUSH (Ayurveda, Yoga and Naturopathy, Unani, Siddha and Homeopathy) doctors, an Auxillary nurse-midwife (ANM) or Staff Nurse and a pharmacist cum data manager. This ensures effective utilization of local practitioners, especially in areas of scarcity of allopathic doctors. Since the MHT are competent to screen and refer children identified with any of the select health conditions to higher centers, there is no compromise in the quality of services rendered. At least two teams cater to a block, covering 80,000 to 1,20,000 population. Advance preliminary micro-planning and multi-sectoral collaboration is required for community screening in the AWC or school. Sites are mapped, team members/ volunteers identified, children identified and scheduled to cover 125 children per day per centre, and all stakeholders notified. The site and team are prepared so that the requisite equipment (tools, charts, instruments, cards, kits, etc.) are available.

The Screening Tool (ST) is used by the MHT to identify all the 4D's, and is age sensitive. The 0-6 years ST includes the following sections; 'Look' (identification of nutritional status, skin conditions, birth defects, deficiencies and diseases including dental problems using multi-purpose pictorial charts or photographs), 'Ask' (condition specific questions that are coded) and 'Perform' (measuring anthropometry and blood pressure, general physical examination, and administration of tools that monitor development and identify developmental delay). NMI specific examination detects abnormalities in symmetry, posture, tone and/or movement in children from 0 to 30 months. Pictures are used for the identification of acquisition of developmental milestones covering 2 to 30 months, NMI, problems in vision, hearing, language, and cognition and 'autistic behaviors'. The ST also includes an 'Autism Specific Questionnaire' for screening 15-24-month-olds (sometimes also in older children). In children between 30 months and 6 years, delays in gross motor, fine motor, speech, cognition, social and impairment in vision/hearing are identified based on questions specifically designed to detect: *i*) difficulty in reading, writing or simple calculations; *ii*) difficulty in sustaining attention; *iii*) difficulty in learning new things; *iv*) delay in walking; *v*) stiffness or floppiness and/or reduced strength; *vi*) difficulty in seeing (without spectacles); *vii*) fits, convulsions; *viii*) loss of consciousness; *ix*) difficulty in speaking; *x*) speech differing from peers; and *xi*) difficulty in hearing (without a hearing aid). The ST (6-18 years) has minor differences from the younger version. There are 9 questions as the items related to speech and convulsions are absent. In this age group 'difficulty in reading…' and 'difficulty in sustaining attention…' are interpreted as LD and ADHD, in contrast to 'delayed cognition' used in children aged <6 years.

All children between 0-6-years are assessed for squint, VI and ocular abnormalities using a pictorial tool, the 'Vision development questionnaire' and a kit (torch, occluder, toys and raisins) for checking some items, while the Snellen's Chart is used in older children. Referrals for VI include infants born preterm (for retinopathy of prematurity), abnormalities detected in the Vision development questionnaire or vision less than 6/12 or a 2-line difference between both eyes (even if both pass). HI is captured by multiple screening modalities, primarily related to understanding and speech; delay in speech and language (0-18 months), difficulties in hearing elicited by the ST questions; and delays identified by the Language Evaluation Scale Trivandrum (LEST) in 0-6-year-olds.

The ST has six sections: Section A for contact details (a unique 15-digit ID number, Mother and Child Tracking System number, aadhar number and District Information System for Education code); Section B for anthropometry; Section C for defects, deficiencies and diseases; Section D for developmental delays, NMI and ASD in 0-6-year-olds, and ADHD and LD in 6-to-9-year-olds; Section E for the Adolescent Specific Questionnaire; and Section F for synthesis and interpretations. On completion, the health care worker decides whether the child is healthy with typical development or requires referral. Parents are counselled accordingly. Diseases and deficiencies are referred to nearby health facilities according to the severity of condition i.e., primary health centers, district centers or hospitals (DH); Severe Acute Malnutrition to Nutritional Rehabilitation Centers; Developmental delay, disability and birth defects to the District Early Intervention Centre (DEIC) attached to the DH; and adolescents to Adolescent Friendly Health Clinics or DEIC. Contact details are provided and free transportation arranged. The MHT maintains a registry of screening and referral and sends monthly reports to the block nodal officer.

Early Intervention Services provided at the DEIC

The aim of RBSK is that each DH should have a mother and child wing with a DEIC (for 0-6-year-old children with delay/ disability) that has physical and functional linkages with a SCNU (to cover all discharged high-risk new-borns), and paediatric facility (for birth defects, diseases and deficiencies). Operational guidelines for the development of a DEIC in terms of outlay, infrastructure and equipment are available on the National Health Mission Portal [9]. Its purpose is to deliver free, evidence-based, transdisciplinary evaluative (clinical, dental, psychometric, hearing and visual assessment and basic laboratory investigations) and intervention services (medical, dental, physiotherapy, occupational therapy, sensory integration, special education, speech therapy, visual stimulation, nutritional rehabilitation, etc). Older children are managed in health facilities, with the DEIC acting as a linkage point.

The DEIC team comprises of trained paediatricians, medical officers, staff nurses, clinical psychologist, optometrists, audiologist/ speech and language pathologist, occupational therapists/ physiotherapists/ developmental therapists, special educators, ECHO technician and medical social worker. A few specialists (ophthalmologist, ENT specialist, Orthopedician etc, visit on a weekly basis. Children who were referred but in whom delay, disability or impairment is not diagnosed are given developmental supportive anticipatory parental guidance. An Individualized Education and follow-up plan is prepared by the team with full participation of the family, for those with a confirmed diagnosis. Standard Operating Procedures and guidelines for management of individual disabilities are in various stages of development to ensure a basic level of quality across all centers. The DEIC manager maintains a map of tertiary care facilities (Government/ empanelled private sector institutes/ Non-Government Organizations) for tertiary level referral. Conditions that need tertiary level care are supported by NHM at pre-defined fixed rates. The 'DEIC Register' maintains the records of all outcomes.

Monthly reports are captured through a chain comprising of DEIC manager, District nodal officer, State Nodal officer and representative of the Child Health Division of the MoHFW. In areas where DEICs are yet to be established, health camps are periodically organized by the state governments for in-depth evaluation of children who screen positive. Professionals use dedicated equipment to determine final diagnoses and further management. As a result, it is ensured that 'no child is left behind'.

Current Status of the RBSK Program Roll-out

The roll out of RBSK has been ensuing throughout the country since 2013 in a phased manner. Currently, there are 238 operational DEICs all over India. These are distributed in the 8 North-East (NE) states, 11 non-NE High Focus states (Bihar, Chhattisgarh, Himachal Pradesh, Jammu and Kashmir, Ladakh, Jharkhand, Madhya Pradesh, Odisha, Rajasthan, Uttar Pradesh and Uttarakhand), 11 Non-high focus states and 7 Union Territories (**Fig**. **1**). Two Model Early Intervention Centers are situated in Kolkata and Noida. Jawaharlal Nehru Medical college (Aligarh Muslim University) has established a state-of-the-art paediatric cardiac catheterization centre with support of NHM, and is currently providing free complex cardiac surgeries for RBSK beneficiaries. The Post-Graduate Medical Education and Research Institute, Kolkata has been the nodal collaborating centre for training since 2013. Sixty-two batches of RBSK recruited professionals have been imparted hands-on training in the assessment and management of children <6 years with developmental delay/ disabilities. Till date, 852 trainees from across India have attended 2 weekly courses, covering 602 days.

Table I depicts the magnitude of children between 0 -6 years who were screened annually from 2014 to 2020; identified with any 4D; availed RBSK services; diagnosed with delay or disability; and were managed at the DEIC. The gradual increase in numbers over the years is probably a reflection of expansion of operational centers, growing awareness and confidence of the public that they will receive optimal health care. **Table II** and **Fig. 2** depict the distribution of children screening positive with individual delay/ disability or impairment. Vision impairment is the most common disability that required referral: 40% (0-6-year) and 80% (6-18-year). In younger children VI is followed by language delay and HI, whereas in the older group VI is followed by HI, and language delay and learning disorder share third position. This observation substantiates the need for implementation of international recommendations of universal hearing and vision screening of young children.

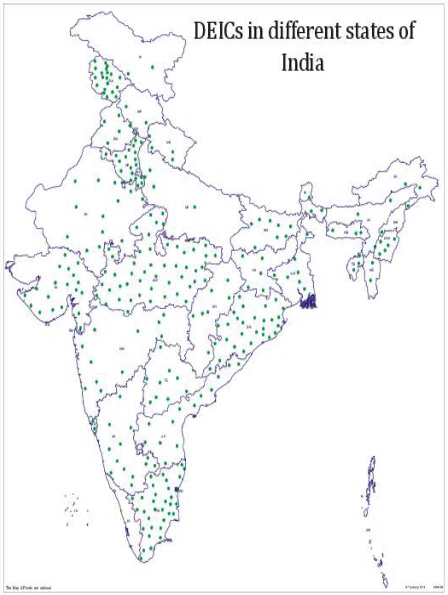

Fig. 1 Location of district early intervention centers (DEICs).

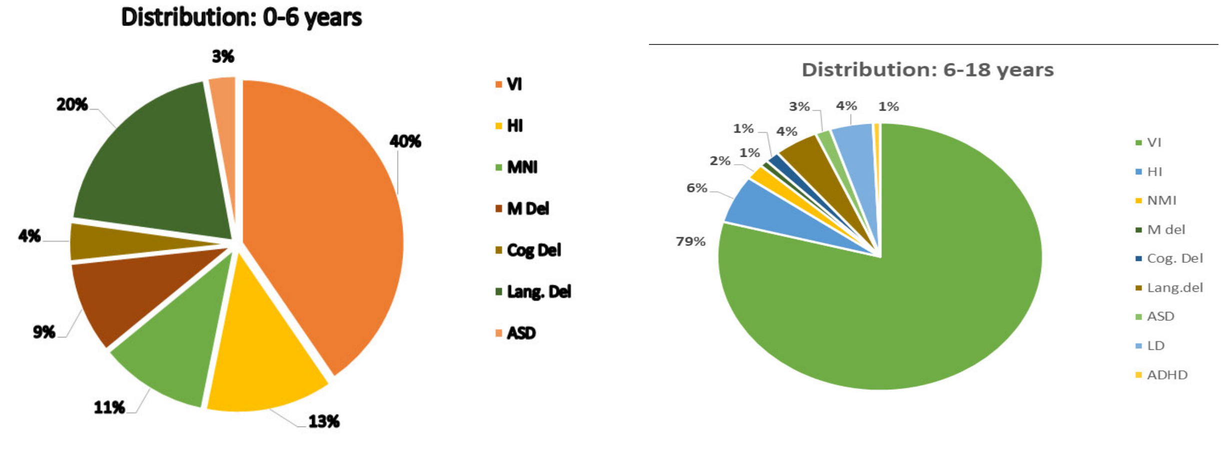

Fig. 2 Distribution of children with individual delay/disability or impairment among beneficiaries in 2019-2020.

Table I Number of Children Between 0 to 6 Years Screened and Managed Under the RBSK Program (2014-2020)

Financial year	*Total screened*	*4Ds identified*	*Availed services for 4 Ds*	*Delay/ disability*	*Trans-disciplinary EI at DEIC*
2014-15*	3,71,59,012	1,13,85,024	22,17,612	14,26,654	-
2015-16	8,36,00,126	41,73,987	13,45,784	3,22,196	83,327
2016-17	8,59,71,276	46,92,160	15.91.302	2,82,549	95,864
2017-18	9,14,28,021	44,16,835	24,44,712	2,22,866	1,25,109
2918-19	9,50,22,552	52,10,064	21.34.631	2,44,735	1,29,376
2019-20	10,04,10,009	71,96,857	36,33,420	3,23,272	1,70,651

*Values in no. DEIC-district early intervention center; EI-early Intervention; 4 D Defects-diseases, deficiencies, and developmental delay/ disabilities. *Consolidated data including those aged 6-18 year, as individual breakup is not available.*

Table II Number of Children Identified With Developmental Delay/Disability (2014-2020)

Disorder	*Age (y)*	*2014-15*	*2015-16*	*2016-17*	*2017-18*	*2018-19*	*2019-20*
Vision impairment	0-6	9,40,133	1,19,640	1,00,492	45,747	89,596	1,30,528
	6-18		10,87,870	10,32,786	4,93,235	10,43,074	10,45,853
Hearing impairment	0-6	1,11,570	23,900	26,652	17,693	18,972	41,514
	6-18		93,495	79,130	58,785	48,838	76,086
NMI	0-6	71,856	45,015	34,617	28,839	30,052	35,309
	6-18		82,674	37,169	25,188	24,153	25,089
Motor delay	0-6	41,842	27,915	24,673	21,607	24,604	29,476
	6-18		45,063	14,595	11,430	11,556	10,523
Cognitive delay	0-6	50,166	14,189	17,265	11,929	11,436	12,506
	6-18		54,068	26,663	21,156	18,883	18,016
Language delay	0-6	74,939	69,310	64,071	55,885	62,059	64,308
	6-18		81,751	65,174	64,200	57,120	58,574
Autism spectrum disorder	0-6	38,353	12,227	9,177	6,153	7,950	9,630
	6-18		36,147	19,467	13,812	11,107	19,158
Learning disorder	0-6	80,556	NA	1,735	18	66	1
	6-18		98,766	74,669	52,140	54,375	56,684
ADHD	0-6	27,998	NA	3,867	122	-	-
	6-18		40,771	19,502	11,430	11,551	8,940

ADHD Attention deficit hyperactivity disorder; NA Not applicable; NMI neuromotor impairment. The years in consideration are financial years. The data for 2014-15 is consolidated for both age groups as 0-18 years.

Future Vision

The last 6 years have definitely been an exciting phase of discovery and expansion for the RBSK team that spans officials in the MoHFW to community health workers in the field. The numbers of operational centers and trained personnel have increased rapidly. The existing gaps in the peripheral health system have been effectively bridged by involving community health workers and alternate branches of medicine in a way that ensures no compromise in quality. The transdisciplinary collaborative philosophy of the program is managing to achieve a paradigm shift from an approach that focused on treating developmental issues in a child as separate non-connected entities, to a holistic, synergistic and inter-related approach that treats the child as a whole. Technology and software is being used for registration, tracking and monitoring which ensures that no child is missed or no child gets lost on the way.

As the number of DEICs, national collaborating centers and state-of-the-art specialized centers are established, RBSK is in the process of standardizing intervention models for each disability. Standard operational protocols are being developed that will outline essential trans-disciplinary steps

KEY MESSAGES

- The Rashtriya Bal Suraksha Karyakram is an Indian indigenous systemic response to ensure universal health coverage for children aged 0-18 years, with special emphasis on early childhood development of children under 6 years of age.
- Screening is done by trained generalists. Quality is ensured by the use of standardized age-appropriate, screening formats and job aids. An evidence-based algorithmic approach identifies 37 chronic health conditions including 9 delays/disabilities.
- Identified children are supported under National Health mission to address out-of-pocket expenses and thus ensure service availability of children in the country.
- Referred children below 6 years receive evidence based, free of cost, trans-disciplinary early intervention services at District Early Intervention Centers.

and components that can be customized according to each child's strengths and weaknesses. This will ensure consistency of high-quality evidence-based service across centers. Pathways for smoother transition of service delivery of children below 6 years at the DEIC to the DH and other facilities once they grow older are evolving. Services will expand to include easy availability of assistive devices, smooth integration of these children into the educational system, disability certification, formation of parent support groups and social support services.

Synthesis and understanding of data from all the corners of the country will ascertain health needs, and thus direct health policy. Collaborative research will advance the understanding of diseases, and developing intervention that are evidence based and effective, but also conducive to the diverse cultural and socio-economic context that is unique to India. One of the long-term goals is the initiation of diploma/ degree training courses of rehabilitation professionals for capacity building and self-sustenance of the RBSK human resources. Given the progress that has been made over the last few years, and the impetus with which the program is marching ahead, the future indeed seems bright.

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