sarthak
EDUCATIONAL TRUST
Empowering the differently abled

EARLY INTERVENTION SERVICES FOR CHILDREN WITH DISABILITIES IN INDIA

Need, Significance & Efforts by Sarthak

CONTENTS

1. LIST OF ABBREVIATIONS

ABA	Applied Behaviour Analysis
ADHD	Attention Deficit Hyperactivity Disorder
ADL	Activities of Daily Living
ANM	Auxilary Nurse Midwife
ASD	Autism Spectrum Disorder
ASHA	Accredited Social Health Activist
BM	Behaviour Modification
CARS	Childhood Autism Rating Scale
CDAU	Child Development & Assessment Unit [Malta]
CME	Continuous Medical Education
CP	Cerebral Palsy
CSR	Corporate Social Responsibility
CwDs	Child(ren) with Disability
DASII	Development Assessment Scale for Indian Infants
DEIC	District Early Intervention Centre
DQ	Development Quotient
DTLD	Diagnostic Test of Learning Disability
ECSE	Early Childhood Special Education
EIBI	Early Intensive Behaviour Intervention
E-LMSE	Learning Management System
ENT	Ear Nose Throat
FBNC	Facility Based Newborn Care

HI	**Hearing Impairment**
HIV	**Human Immunodeficiency Virus**
IBI	**Intensive Behavioural Intervention**
IDEA	**India Disability Empowerment Alliance**
IEP	**Individualised Education Program**
ILP	**Intensive Language Program**
IQ	**Intelligence Quotient**
ISAA	**Indian Scale for Assessment for Autism**
ISP	**Intervention Support Program**
JSSK	**Janani Shishu Suraksha Karyakaram**
JSY	**Janani Suraksha Yojana**
LIG	**Low Income Group**
MIS	**Management Information System**
MISIC	**Malin's Intelligence Scale for Indian Children**
MoHFW	**Ministry of Health & Family Welfare**
MUAC	**Mid Upper Arm Circumference**
NEP	**National Education Policy**
NGO	**Non Governmental Organisation**
NHM	**National Health Mission**
NICU	**Neonatal Intensive Care Unit**
NIMHANS	**National Institute of Mental Health and Neuro-Sciences**
NISH	**National Institute of Speech and Hearing**

NITI [Aayog]	**National Institute for Transforming India**
NPCB	**National Programme for Control of Blindness**
NPCB&VI	**National Programme for Control of Blindness & Visual Impairment**
NPPCD	**National Programme for Prevention & Control of Deafness**
NRHM	**National Rural Health Mission**
NSSO	**National Sample Survey Office**
OT	**Occupational Therapy**
PDA	**Patent Ductus Arteriosus**
PwDs	**Person(s) with Disability**
RBSK	**Rashtriya Bal Swasthya Karyakram**
RCH	**Reproductive & Child Health**
RIO(s)	**Regional Institute(s) of Ophthalmology**
RPwD Act	**Rights of Persons with Disability Act**
SA	**Social Age**
SDCC	**State Diagnostic and Counselling Centre [Iceland]**
SE	**Special Education**
SQ	**Social Quotient**
ST	**Speech Therapy**
TORCH	**Toxoplasmosis, Other Agents, Rubella, Cytomegalovirus and Herpes Simplex**
UNESCO	**United Nations Educational, Scientific and Cultural Organisation**
UNICEF	**United Nations International Children's Education Fund**

2. LIST OF FIGURES

3. EXECUTIVE SUMMARY

Children with Disabilities (CwDs) account for almost 8 million individuals in India.[1] Often faced with parental denial, social stigma and lack of access to rights and opportunities, this section of the Persons with Disability population experience multiple axes of marginalisation and vulnerabilities. This is only heightened by socio-economic factors including gender and caste.

Early intervention refers to the services and support available to babies and young children with disabilities and/or development delays, particularly over the first 1000 days. It ensures that the child's developmental, health and support needs are met. The intervention encompasses prevention measures, early diagnosis, rehabilitation and therapy and is thus, the key strategy to manage and overcome the effects of disability on young children. It is commonly accepted that early intervention improves and enhances the child's development, enables the best use of the child's skills and increases the chances of future opportunities. Its benefits extend into the individual's adulthood as well, enabling Persons with Disability to integrate better in social environments and become more independent.

Early intervention encompasses prevention measures, early diagnosis, rehabilitation and therapy and is thus, the key intervention to manage and overcome the effects of disability on young children. It is commonly accepted that it improves and enhances the child's development, enables the best use of the child's skills and increases the chances of future opportunities.

There are multiple factors that increase a child's risk of disability. The key risk factors are defects at birth, deficiency, disease, and developmental delays. Defects at birth could include oxygen deprivation, low birth weight or preterm birth. Deficiencies commonly affect the child's weight, height and other physiological parameters. Developmental delays can be due to genetic factors, environmental influences and/or economic factors while some diseases can also result in disability and the need for early intervention.

[1]Source: N for Nose: Status of the Education Report for India 2019 - Children with Disabilities," UNESCO [Available at: https://en.unesco.org/news/n-nose-state-education-report-india-2019-children-disabilities]

Early intervention is often understood as comprising of activities and therapies following a child's birth and diagnosis. However, the process of intervention begins much earlier, encapsulating preventive measures that can be taken before the birth of the child. Following the birth and diagnosis of the child, early intervention includes occupational and physical therapy, speech therapy and special education. These various therapies are provided by Sarthak through the organisation's Antakshep Kendra. Apart from these therapies, Sarthak also provides families access to counselling and pediatric consultation while also adopting a multistakeholder approach in ideating early intervention strategies for children.

Sarthak works with Children with Disabilities by providing occupational and physical therapy, speech therapy, special education and behavioural modification. The organisation also provides families with access to counselling and consultation, both online and offline. All interventions at Sarthak adopt a multi-stakeholder approach and involve working with families, educational institutions, different therapists and so on.

The interventions and conversations around early intervention are set against the backdrop of national schemes and policies that encourage diagnosis and early care. These initiatives have been crucial in creating an atmosphere where early intervention is given the importance it deserves. The Rashtriya Bal Swasthya Karyakram (RBSK) is important initiative dedicated to early intervention for CwDs. Launched by the Ministry of Health & Family Welfare, it focuses on early identification and intervention for children from birth to 18 years of age. The National Education Policy of 2020 also stresses on the need for equal participation of CwDs in formal education. Along with the numerous other schemes and policies, these form the foundation of all early intervention strategies in India. This report locates Sarthak's efforts in the early intervention sector within this context as well.

While there has been significant improvement in the area, there is much that remains to be done. This report concludes with recommendations pertaining to collecting disaggregated data about CwDs, reaching more children through personalised interventions, and building an ecosystem of collaboration between organisations in the disability sector.

4. UNDERSTANDING CONTEXT

While there is no universally accepted standard definition for disability, the International Classification of Functioning, Disability and Health defines it as the "limitation in performance of socially defined roles and tasks within a sociocultural and physical environment."[2] This definition encompasses multiple forms of disability including physical and/or sensory impairments as well as intellectual and/or developmental delays.

About 1 billion people around the world have some form of disability.[3] Of this population, about 80% are believed to live in developing countries.[4] According to the 2011 census, there are 26.8 million people in India with disability. Of the 26.8 million people with disability, the largest percentage belong to the age group 10-19 years. This age group accounts for 17% which constitutes 4.6 million people. Within the age group of children between 0 to 6 years with disabilities, about 18% have visual disability, 23% have hearing disabilities, 5% have speech disabilities and so on. Refer Figure 1 for a more detailed distribution of the disabilities amongst children in this age group.

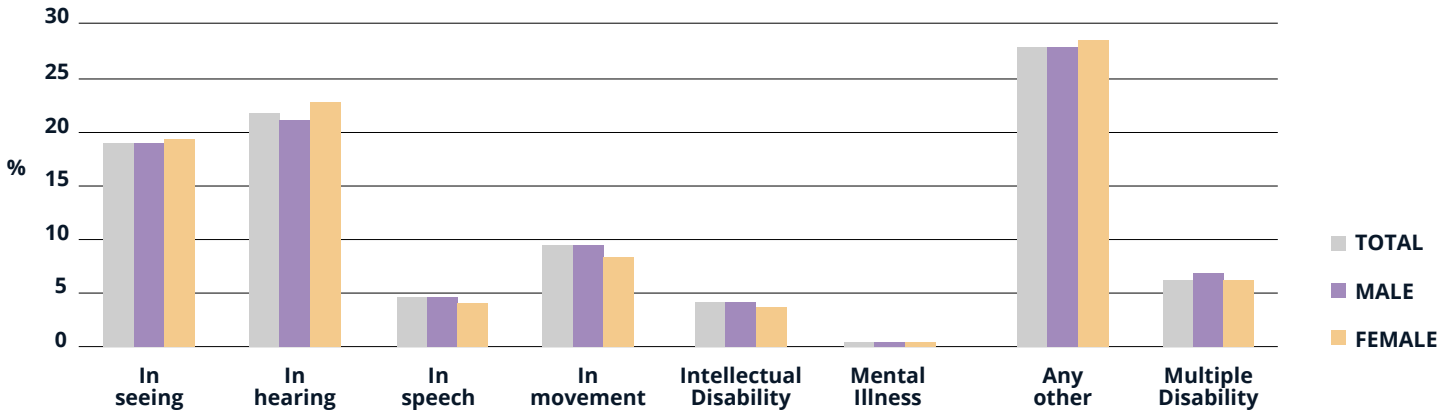


Fig 1: Types of disabilities among children (0-6 years) in India

Studying the status of Children with Disabilities (CwDs) in India is hindered by unavailability of data, particularly information disaggregated by age, gender or geographic location. What data is available often looks at the age bracket of 5 to 19 years. While this age bracket is older than the children who benefit from early intervention, it provides useful context of the status of CwDs in India.[5]

[2]Source: Towards a Common Language for Function, Disability and Health [Available at https://academic.oup.com/view-large/190901665]

[3]Source: Disability Overview, World Bank [Available at: https://www.worldbank.org/en/topic/disability]

[4]Source: Factsheet on Persons with Disabilties, United Nations

[5]Source: All statistics as well as Figures 1 to 4 have been sourced from 'Disabled Persons in India: A Statistical Profile 2016' [Available at: http://mospi.nic.in/sites/default/files/publication_reports/Disabled_persons_in_India_2016.pdf]

Among the CwD population between the ages of 5-19 years, according to the Census 2011, 27% had never attended an educational institution whereas 12% had attended such institutions in the past (Figure 2). The proportion of males attending these institutions was at 57% which was higher than that of females in the same age group (43%, refer Figure 3). Additionally, the percentage of children with disabilities attending school was higher in urban areas (65%) as compared to rural areas (60%, refer Figure 4). These numbers point towards the need for early intervention in order to prepare children with disabilities as well as educational institutions for schooling. In the absence of such preparation, CwDs risk dropping out of education, being unable to gain admission or facing difficulties in coping with mainstream curricula.

While these numbers are telling, it is important to contextualise their analysis. At the time of the 2011 census, only seven disability categories were recognised by the Disability Act of 2005. With the introduction of the Rights of Persons with Disabilities (RPwD) Act of 2016, this number rose to 21 disability categories. Thus, it is likely that these statistics present an incomplete picture.

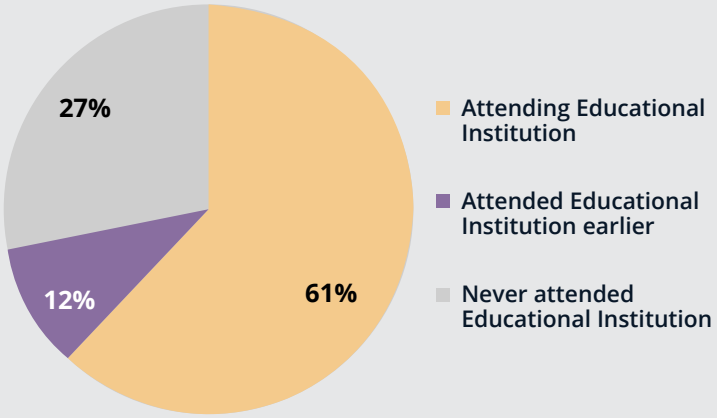


Fig 2: School attendance of CwDs between 5-19 years of age

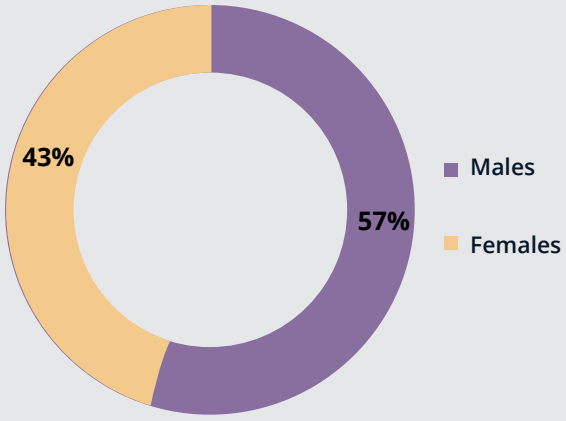


Fig 3: Percentage of CwDs attending school by gender

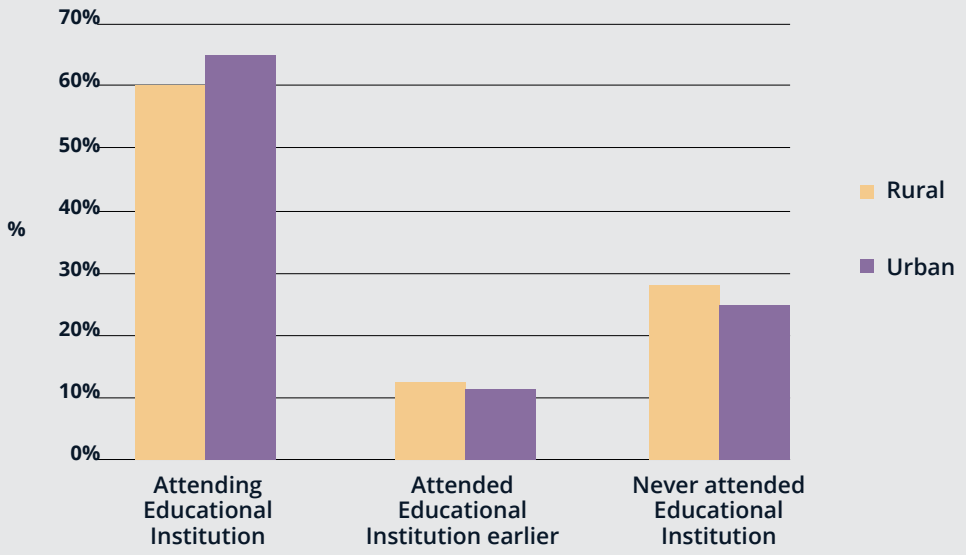


Fig 4: Percentage of CwDs attending school by residence

The RPwD Act, which increased the number of disability categories that was recognised by the law, has set the context for many interventions in the disability sector since 2016. The Act "promotes and protects the rights and dignity of people with disabilities in various aspects of life – educational, social, legal, economic, cultural and political."[6] The expanded recognition of disabilities seeks to provide benefits, opportunities and legal recourse as necessary. Disabilities under the purview of this Act are described in Figure 5.

PHYSICAL DISABILITY
Including locomotor disability, leprosy-cured persons, cerebral palsy, dwarfism, muscular dystrophy, acid attack victims, blindness and low vision, deaf and hard of hearing, speech and language disabilities

INTELLECTUAL DISABILITY
Including specific learning disabilities and the autism spectrum disorder

MULTIPLE DISABILITIES
Simultaneous occurrence of two or more disabilities

NEUROLOGICAL OR BLOOD DISORDERS
Including multiple sclerosis and Parkinson's disease, haemophilia, thalassemia and sickle cell disease

MENTAL DISABILITIES
Including disabilities arising from mental illness

Fig 5:
Disabilities covered under the RPwD Act, 2016

While the Census and the RPwD Act have had significant positive impact on the conversation around disability, the population of PwDs continue to experience social exclusion, lack of opportunities and other challenges such as negative attitudes from people around them. Within this population, there are layers of added marginalisation and vulnerability. One of the communities that experience this multiple marginalisation are CwDs. CwDs often bear the impact of parental denial, social boycott and the denial of rights, including the right to access to property and human rights.[7] Girls with disability are more vulnerable to such impact.

[6]Source: The Rights of Persons with Disabilities Act accessed from Diversity and Equal Opportunity Centre [Available at: https://deoc.in/the-rights-of-persons-with-disabilitiesrpwd-act/]

[7]Source: Janardhana, N, D Muralidhar, DM Naidu, and Guru Raghevendra. (2015) "Discrimination against Differently Abled Children among Rural Communities in India: Need for Action." https://doi.org/10.4103/0976-9668.149070.

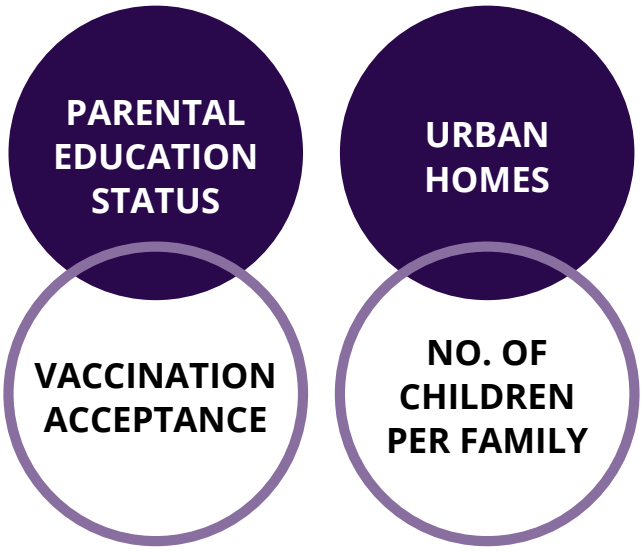


Fig 6: Factors Contributing to Early Referrals for Intervention

According to a report by UNESCO, 1.7% of the overall population of children in our country are CwDs, totalling to almost 8 million children. About 1% of children between the age of 0 and 4 live with a disability, amounting to 12,91,637 individuals.[8] Given this sizeable population, CwDs require specific policy attention as well as dedicated programs for early intervention. This early intervention is particularly important in the Indian context to enable increased literacy and acceptance of CwDs. By adopting early intervention methods, the children will benefit from early diagnosis, rehabilitation, and better growth and development. Thus, early intervention strategies become key to managing and overcoming the effects of disability in young children. Some of the factors contributing to early referrals for intervention are described in Figure 6.[9]

[8]Source: "N for Nose: Status of the Education Report for India 2019 - Children with Disabilities," UNESCO [Available at: https://en.unesco.org/news/n-nose-state-education-report-india-2019-children-disabilities]

[9]Source: : Juneja, Monica, Rahul Jain et al. (2014) "Indian children with developmental delays: early versus late referral for intervention." https://pubmed.ncbi.nlm.nih.gov/24691576/

5. UNDERSTANDING EARLY INTERVENTION

Early intervention is “the term used to describe the services and supports that are available to babies and young children with developmental delays and disabilities, and their families.”[10] The National Institute for Mentally Handicapped defines early intervention as “special services for infants and toddlers at risk for developmental delays.”[11] It refers to specialised support for children and families in the early years of life, from birth to entry into school. The goal of early intervention is to meet a child’s development, health and support needs.[12] Early intervention thus includes both prevention and identification of developmental delays.

Early intervention efforts focus particularly on the child’s first 1000 days since this is a period of vital physical growth as well as mental development. This period offers an opportunity to build lifelong intelligence and health, often calculated from pregnancy.[13,14] Thus, the first 1000 days are crucial to combatting or diminishing the effects of possible delays or disabilities.

According to UNICEF, the time between pregnancy and age 3, when the brain is most susceptible to environmental influences, is critical for a child’s growth and development. All children - including those with disabilities and developmental delays, those living in poverty or deprivation, and those affected by conflict or displacement - need nurturing care and health services to survive and thrive.

Early intervention has been defined by the World Health Organisation as a systematic and planned effort to promote development through a series of manipulations of environmental or experiential factors, initiated during the first five years of life.

Source: Health & Child Development, UNICEF | Development difficulties in Early Childhood, WHO

[10]Source: What is "Early Intervention"?, Centers for Disease Control and Prevention

[11]Source: Organization of Early Intervention Services, National Institute for the Mentally Handicapped

[12]Source: What is "Early Intervention"?, Centers for Disease Control and Prevention

[13]Source: Journey of the First 1000 Days, Rashtriya Bal Swasthya Karyakram [Available at: https://nhm.gov.in/images/pdf/programmes/RBSK/Resource_Documents/Journey_of_The_First_1000_Days.pdf]

[14]Differing definitions of early intervention focus on the first five years after birth, first three years after birth, or 1000 days since pregnancy planning. It is important to keep in mind these differing definitions when addressing issues of early intervention.

Early intervention strategies commonly focus on four categories of skills that contribute to a child's overall development. These categories are motor, language and speech, cognitive and social development:[15]

- Motor development refers to gross and fine motor skills: These include standing, holding, jumping, eating, writing, bathing and grooming.
- Language and speech development includes communication skills: These skills refer to sound vocalisation, phrases and sentence formation.
- Cognitive development includes developing understanding, thinking and perception.
- Finally, social development refers to making friends, playing with other children and sharing one's belongings with others.

Apart from these domains, child development can also be understood with the help of development milestones. Developmental milestones refer to certain basic milestones that mark expected development in keeping with the chronological age of a child. Development delays are understood as a consistent lag in attaining these milestones. The presence of these delays calls for a detailed diagnosis of the child.

Key development milestones describe when children are expected to sit, stand and walk, and how they are expected to react to other individuals. Figure 7 contains the list of some key developmental milestones.

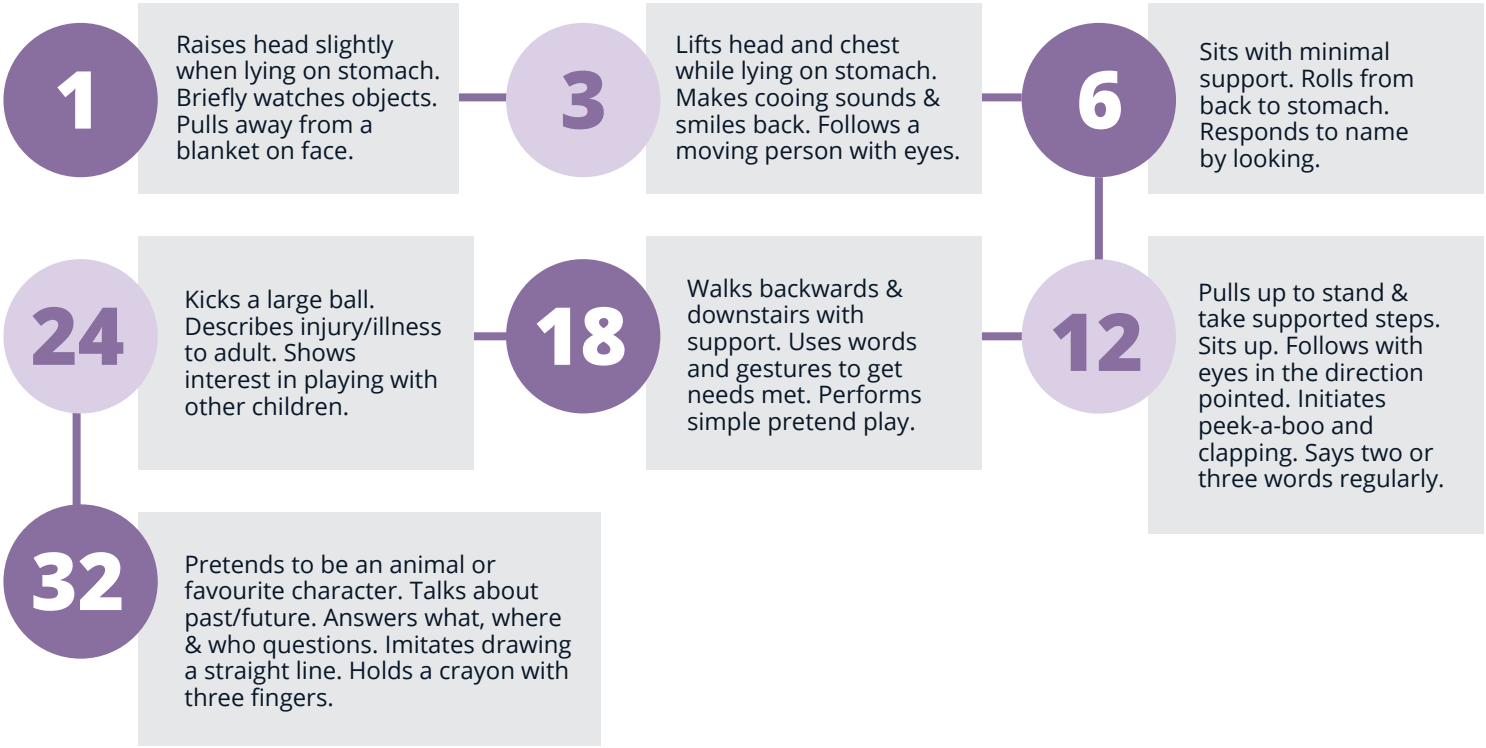


Fig 7: Key Development Milestones (in months)

[15]Source: Major Domains in Child Development, VeryWellFamily

5.1 FACTORS INCREASING RISK OF DISABILITY

Successfully achieving key development milestones suggests the normal progression of a child. However, in some situations, the child's growth indicator (physical size) and/or development indicator (skills and function) get affected. This results in a failure to achieve these development milestones, affecting the physical, intellectual, social and emotional wellbeing of the child. There are multiple factors which increase the risk of disability and developmental delays in a child. Rashtriya Bal Swasthya Karyakram's 4D framework – of defects at birth, deficiency, disease and developmental delays - helps understand these factors. At the point of enrolment in Sarthak's Early Intervention services, the team takes note of all factors in the 4D framework based on medical reports, discharge slips and parent interactions.

DEFECTS AT BIRTH

There are numerous factors which could potentially lead to complications during labour and delivery that result in defects at the birth of the child. Trauma, which is an important risk factor resulting in birth defects, could be due to oxygen deprivation, preterm birth (prematurity), low-birth weight and/or post-term birth.

Oxygen Deprivation: Oxygen deprivation (or anoxia) prior to or during the birth process can be a result of premature separation of the placenta or the umbilical cord being wrapped around the baby's neck causing inadequate oxygen supply. Deprivation of oxygen can result in a child having cerebral palsy, a term used for a variety of problems resulting from brain damage before, during or just after birth. Newborns sometimes fail to start breathing immediately after being born. The risk of brain damage can result from delayed breathing of more than three minutes after birth. The effect of oxygen deprivation generally causes intellectual delays and/or physical disabilities such as blindness, hearing impairments and motor delays. If the oxygen deprivation is severe, such problems will persist beyond early childhood as well.

Low Birth Weight: Birth weight is a good predictor of infant survival and healthy development. For a full-term pregnancy (40 weeks), a healthy average weight is considered to be between 2.56 kilograms and 3.79 kilograms.[16] Infants may have low birth weight because of prematurity and/or intrauterine growth delays due to genetic makeup or an unfavourable uterine environment.

[16]Approximate conversion from 5 pounds 11 ½ ounces and 8 pounds 5 ¾ ounces

Infants born with low birth weight face health complications such as immature lungs and breathing, mild/severe cognition problems, cerebral palsy, delayed speech and/or sensory impairments (visual and auditory). Infants weighing less than 1.13 kilograms[17] at birth experience more extreme long-term difficulties that sometimes cannot be overcome. These infants usually need intensive neonatal care for survival and typically require lengthy stays in the hospital.

Preterm Birth (Prematurity): Preterm infants are born several weeks before completing 37 weeks of gestation, regardless of birth weight. Various factors are associated with premature birth. The most common of these include teen pregnancies, poor prenatal care, drug abuse and maternal trauma. Preterm infants commonly have respiratory problems due to underdeveloped lungs. Brain haemorrhaging and/or immature immune systems could also be complications of preterm birth. Deficits in motor coordination, inattentiveness, over-activeness and frequent illnesses are some of the difficulties that continue into the primary years.[18]

Preterm babies are sometimes irritable, unresponsive and suckle poorly. Due to these problems, some parents become less sensitive and responsive in caring for them. Preterm babies are less often cuddled, touched and talked to, especially those who are very ill at birth. According to Patteson and Barnard (1990), experts in the field of early childhood development as well as mother-newborn interactions, mothers become overly intrusive by poking and verbally commanding the children in an effort to receive a response from a passive baby. Such behaviours could further contribute to delays in development in pre-term children.

Post-Term Birth: Post-term babies are infants that are born after 42 weeks. Approximately 5% of women deliver after 42 weeks. A concern with post-term babies is the possibility of squeezing the umbilical cord if there is a drop in the amount of amniotic fluid. In addition, the foetus would have grown larger during the extra weeks in the uterus which may cause the baby to experience difficulty moving through the birth canal. Increased risk of oxygen deprivation and head injuries occur in post-term births.

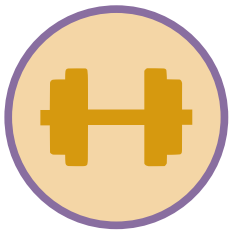
[17]Approximate conversion from 2 ½ pounds

[18]Source: McCormick MC, Gortmaker SL, Sobol AM. (1990) "Very low birth weight children: behavior problems and school difficulty in a national sample." doi: 10.1016/s0022-3476(05)83322-0.

DEFICIENCY

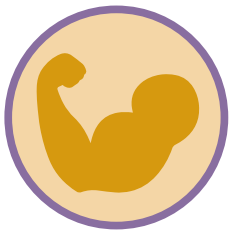
Assessing the nutritional status of a child is crucial. Nutritional deficiencies result in higher chances of the child being prone to disability.[19] A nutritional assessment of a child usually includes measurements of multiple bodily markers, allowing for healthcare practitioners to identify deficiencies in children. Some of these measurements are as follows.

Weight measurement: It is the most widely used anthropometric measurement for the evaluation of nutritional status. This is because it indicates body mass and sensitivity to even small changes due to childhood morbidity like diarrhoea. Furthermore, rapid weight loss suggests potential malnutrition.



Height measurement: Another parameter for the nutritional assessment of a child is height. Genetic and environmental factors (such as nutrition, infection) cast influence over the height of an individual.

Mid Upper Arm Circumference (MUAC): It suggests the status of muscle development. In general, children have a constant arm circumference of approximately between 12.5 and 13.5 centimetres between the ages of 1 and 5 years. MUAC measurement helps in identifying malnutrition and mortality risk in children. It correlates well with weight or height.



Body Fat: Deficiency of protein and calories affects soft tissues in muscles and fat. Thus, body fat is also considered as a measurement of malnutrition. However, as the values differ in different communities, local standards are used for comparison, and this measurement is usually used by researchers and academics.

[19]Groce, N., Challenger, E., Berman-Bieler, R., Farkas, A., Yilmaz, N., Schultink, W., Clark, D., Kaplan, C., & Kerac, M. (2014). "Malnutrition and disability: unexplored opportunities for collaboration" https://doi.org/10.1179/2046905514Y.0000000156

Head and Chest Circumference: Under general circumstances, the head size corresponds with brain size and increases rapidly during infancy. At birth, the head circumference of a child is 34 centimetres and the chest circumference is 32 centimetres, and by the age of 6-9 months, both become equal. However, in an undernourished child, the head circumference remains larger even at the age of 3 years, due to poor development of the thoracic cage.

	BIRTH	1 YEAR	2 YEAR	3 YEAR	4 YEAR	5 YEAR
WEIGHT (in kgs)	2.5-3.5	8.9	12	14.2	15.4	17.9
HEIGHT (in cms)	50	75.7	85.5	94	100.3	107.9
MUAC (in cms)	12	13	13	13	13	14.5
HEAD (in cms)	35	46	47	50	52	54

Fig 8: Normal Ranges for Nutritional Assessment Parameters

DEVELOPMENTAL DELAYS

While nutrition and its associated markers play a key role in identifying developmental delays, there are non-nutritional, environmental causes of delayed growth and development as well. These include the following:

Genetic Inheritance: Genetic factors affect the height and weight, mental and social development, and personality of a child.

Pre-Birth and Post-Birth Nutrition: Nutritional deficiency in a pregnant woman and in a child after birth may result in intellectual disabilities.

Infections and Infestations: Infection with TORCH[20] during intrauterine life negatively influences the growth of the foetus. Further, recurrent infections like diarrhoea and measles, especially in a malnourished child, adversely affect the child's growth.

Physical Surroundings: Air and light ventilation as well as hygiene also affect growth and development.

Psychological Factors: Love, care and proper child-parent relationships also have an impact on the child.

[20]TORCH is an acronym which refers to Toxoplasmosis, Other Agents, Rubella (also known as German Measles), Cytomegalovirus, and Herpes Simplex.

Economic factors: Very poor economic conditions can lead to nutritional deficiency. This can also be exacerbated by poor access to medical facilities.

Other factors: Birth order, birth spacing and education of parents also play significant roles in the growth and development of a child.

DISEASE

Apart from deficiencies and defects at birth, certain diseases increase the risk of a child developing a disability. These diseases include but are not limited to polio infection, malaria, meningitis, leprosy, Human Immunodeficiency Virus (HIV) and measles.[21]

5.2 IMPORTANCE OF EARLY INTERVENTION

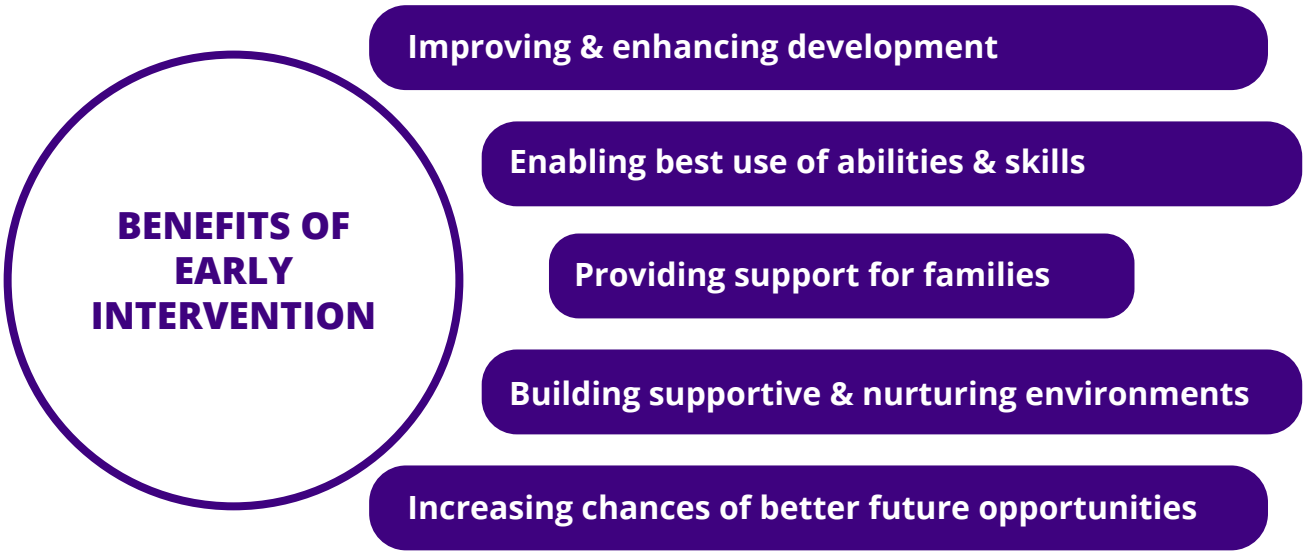


Fig 9: Benefits of Early Intervention

Given these various factors that increase risk of disability and the crucial nature of the first 1000 days, the importance of early intervention is evident. Some of the potential benefits of early intervention include improving and enhancing the child's development, enabling the best use of the child's skills and increasing the chances for greater future opportunities.[22] Many of these benefits accrue during childhood. However, it is important to note that the benefits of early intervention are not limited to this stage of life. Addressing developmental delays early in a child's life is known to have benefits even in adulthood, enabling individuals to better integrate in social environments including school, college, communities and workspaces.

[21]Source: Durkin M. (2004) "Control of Infectious Causes of Childhood Disability in Developing Countries' [Available at: https://www.ncbi.nlm.nih.gov/books/NBK83707/]

[22]Source: Benefits of Early Intervention, TEIS

Another common misconception is that early intervention begins following the diagnosis of developmental delays in children. Contrary to this, early intervention spans the process of preventing, identifying and intervening in case of intellectual and developmental disabilities and begins much earlier. Preventive action seeks to lower the risk of developmental delays even in vitro and can be understood as spanning three phases.

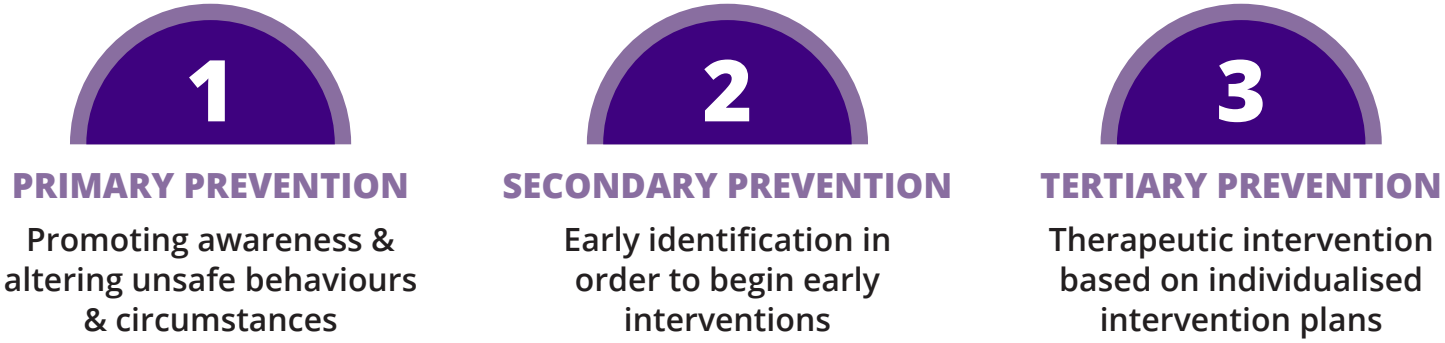


Fig 10: Types of Preventive Action

Primary prevention: This aims at making people aware of the risk factors and ways to prevent disability in children. This is done by avoiding disease or injury by averting exposure to hazards, altering unhealthy or unsafe behaviours, and increasing resistance. Common primary prevention strategies include pregnant women avoiding alcohol and substance abuse. Such behaviour could lead to growth problems, birth defects and/or learning and behaviour problems in the child.[23]

Secondary prevention: Secondary prevention refers to early identification of the issue in CwDs. It aims to reduce the impact of a disease or injury that has already occurred. This is done by detecting and treating disease or injury as soon as possible to halt or slow its progress. It also includes encouraging personal strategies to prevent recurrence of injuries.

Tertiary prevention: Tertiary prevention aims to manage the impact of the disability in children. These interventions thus seek to improve a child's ability to function, their quality of life, and their life expectancy. Tertiary prevention includes Occupational Therapy (OT), Speech Therapy (ST), Behaviour Modification (BM) and Special Education (SE) as per the requirements of the CwD.

[23]Source:Alcohol and Pregnancy, MedlinePlus [Available at: https://medlineplus.gov/ency/article/007454.htm]

There are certain general preventive measures that can be adopted before birth or even before planning for a child. These measures help minimise the chances of disability at birth. These measures include:

- Avoiding marriage between consanguineous relations in order to prevent hereditary disorders.
- Avoiding early or late pregnancies (before the age of 18 or after the age of 35)
- Consulting a doctor before planning pregnancy in case of maternal history of diabetes, Rh negative blood type, incidence of birth defects in family, or difficulty in conceiving, and series of miscarriages, stillbirths, twins, obstructed labour, prolonged labour or severe bleeding in previous pregnancy

Apart from these preventive measures, there are certain precautionary measures to be taken during pregnancy:

- Physical labour such as carrying heavy loads, walking on slippery ground or climbing stools/chairs must be avoided
- Drugs and medications must be taken only under medical supervision
- Substance abuse such as smoking tobacco, alcohol and narcotics must be completely avoided six months before conceiving
- Exposure to x-rays and any kind of radiation must be avoided
- During the first three months of pregnancy, exposure to patients with any kind of contagious or air borne diseases must be avoided
- Sexual contact with a person having venereal diseases must be avoided
- Excessive use of chemical-based cosmetics must be avoided
- In case of edema (swelling) of feet, persistent headache, fever, difficulty or pain in passing urine, bleeding from the vagina, and yellowness of eyes (jaundice), a doctor must be immediately consulted

- A diet with green leafy vegetables, proteins and vitamins should be consumed
- Women in child-bearing age must ensure intake of 0.4 mg of folic acid daily, specifically during the third trimester, when the risk of developing iron deficiency or anaemia is highest

GENERAL PRECAUTIONS

Avoid consanguineous marriages
Avoid physical labour
Medication only under supervision
Avoid susbstance abuse

Avoid early/late pregnancies
Avoid exposure to radiation
Be cautious of contagious diseases
Avoid contact with those with STDs

Consult doctor when planning pregnancy
Avoid chemical cosmetics
Consult doctor when in need

Fig 11: General Preventive Measures

While the phases and precautions associated with prevention trace the lifecycle of an individual and illness, other models of early intervention focus more on environmental and sociocultural factors influencing the child and the family.

Ecological Model: It works on linking the family environment to child development.

Social Support Model: It focuses on parents and families of children with disability.

Developmental Systems Model: It works for both biologically and environmentally vulnerable children. An important feature of this model is that it focuses on "maximising family patterns of interaction by addressing potential stressors related to risk and disability conditions."[24]

[24]Source:Guralnick, Michael J. (2001) "A Development Systems Model for Early Intervention" [Available at: https://depts.washington.edu/chdd/guralnick/pdfs/dev_sys_model_EI_IYC_10_01.pdf]

Sarthak has drawn from the best practices of these models to create a unique model of intervention. This model includes:

- A multidisciplinary approach towards CwDs in order to address their issues in a holistic manner.
- A no rejection policy to ensure maximum children are able to benefit from access to early intervention.
- Engagement and involvement of parents and caregivers of CwDs to ensure maximum intervention impact.
- Inclusion of home-based activities to ensure continuity of intervention especially in the current COVID-19 context.
- Targeted approach towards each CwD as well as periodical reviews to address areas of concern and note areas of progress.
- Proper engagement of relevant stakeholders to maximise benefits for CwDs.

5.3 THERAPIES USED IN EARLY INTERVENTION

Prevention mechanisms and precautionary measures are an important component of early intervention that cater to the wellbeing of an unborn child. Various therapies exist in order to address the needs of children born with intellectual disabilities or developmental delays despite the adoption of these preventive measures. Each of these therapies focus on different domain areas enabling the child to develop holistically. Sarthak provides these therapies to CwDs based on their individual needs. The team creates an individualised intervention plan through our internal MIS system for every child which is reviewed and monitored every month in order to measure progress. This process allows the organisation to offer multiple therapies to each child in need. Some of the key areas of therapy are as follows:

Physical and Occupational Therapy: Physical therapy focuses on improving function and mobility in order to promote the child's participation at home, school and the larger community. Occupational therapy, also known as OT, focuses on the development of physical or sensory areas. Through this, children become independent and their self-esteem and sense of achievement grows.

Speech Therapy: Speech therapy focuses on developing verbal and non-verbal communication. In order to improve verbal communication, this intervention focuses on speech (words, phrases and sentence formations), expression, reception and comprehension skills. This form of therapy most commonly caters to children with delays and disorders spanning from mild articulation to complex disorders such as autism, Down's Syndrome, hearing impairment, motor speech disorders or other developmental delays.

Early Childhood Special Education (ECSE): ECSE focuses on basic concept building, enabling a child to learn functional academics through appropriate materials. Such ECSE services are provided to young children between 3 to 5 years of age. It encompasses specially designed instructions or related services to make progress in acquiring knowledge and skills. These services focus on improving social relationships and teaching children to take action to meet their needs within the general education program. All education is imparted through a simplistic and playful style of teaching.

Behaviour Modification: Behaviour modification is based on the theory of conditioning that contends that developing a particular behaviour in a child requires constant practice and revision. This ensures that the behaviour gets strengthened in the child. Thus, the aim of behaviour modification is to increase desirable behaviours and decrease undesirable ones, often through the use of reward and punishment techniques.

6. EARLY INTERVENTION IN INDIA

The previous chapter charted the importance of early intervention and its individual components. This chapter seeks to contextualise this information within the Indian scenario.

Given the size of the CwD population in India, early intervention has emerged as a focus area for policy and implementation. The Government has launched multiple interventions to ensure prevention, early identification and early intervention for children with disabilities. Some of these programs, policies and initiatives are particularly relevant. These programs and initiatives are also easily accessible in Sarthak's CapSarathi mobile and web applications. Through this platform, Sarthak provides information on all schemes as well as early intervention centres. This enables parents of CwDs to access services with ease.

NATIONAL EDUCATION POLICY (NEP)

The Ministry of Human Resource Development published the National Education Policy (NEP) in 2020. One focus of this policy is ensuring the inclusion of CwDs and the equal participation of these children in the schooling system. Additionally, it emphasises recruiting special educators with cross-disability training in schools. This would help children have access to resources who understand the requirements of various disabilities. Further, the policy calls for the establishment of resource centres particularly for children with severe or multiple disabilities.[25]

SAMARTH

A scheme under the National Trust of the Ministry of Social Justice and Empowerment, Samarth is a scheme that focuses on respite care for families with CwDs while also providing respite homes for PwDs. Such respite care and residential facilities include provision of basic medical care from professionals apart from adequate and quality care services, and acceptable living standards.[26]

[25]Source: National Education Policy 2020, Ministry of Human Resource Development [Available at: https://www.education.gov.in/sites/upload_files/mhrd/files/NEP_Final_English_0.pdf]

[26]Source: Samarth (Respite Care), The National Trust [Available at: https://www.thenationaltrust.gov.in/content/scheme/samarth.php]

NIRAMAYA

Another initiative under the National Trust of the Ministry of Social Justice and Empowerment, this scheme aims at providing affordable health insurance to PwDs with a coverage of up to Rs. 1 lakh. This covers a comprehensive range of services including diagnostic tests, check-ups, surgeries preventing further aggravation of disability, corrective surgeries, alternative medicines, and ongoing therapies for reducing the impact of the disability.[27]

RASHTRIYA BAL SWASTHYA KARYAKRAM (RBSK)

Neural Tube defect, Down's Syndrome, Cleft lip and/or palate, Club Foot, Developmental dysplasia of the hip, Congenital cataract, Congenital deafness, Congenital heart disease, Retinopathy of prematurity

DEFECTS AT BIRTH

Anaemia, Vitamin A Deficiency, Vitamin D Deficiency (Rickets), Severe Acute Malnutrition, Goitre

DEFICIENCIES

Skin Conditions (scabies, fungal infection, eczema) Inflammation of middle ear (Otitis Media), Rheumatic Heart Disease, Dental Caries, Convulsive Disorders

CHILDHOOD DISEASES

Vision Impairment, Hearing Impairment, Neuro-motor Impairment, Motor and/or cognitive delay, Language Delay, Behavioural and/or learning disorder, ADHD, Congenital Hypothyroidism, Sickle cell anaemia

DEVELOPMENTAL DELAYS & DISABILITIES

Fig 12: Conditions covered under RBSK

[27]Source: Niramaya (Health Insurance Scheme), The National Trust [Available at: https://www.thenationaltrust.gov.in/content/scheme/samarth.php]

Rashtriya Bal Swasthya Karyakram (RBSK) is an important initiative launched by the Ministry of Health & Family Welfare under the National Health Mission (NHM). It aims at early identification and early intervention from birth to 18 years of age at zero cost to the family. It focuses on defects at birth, deficiencies, diseases and development delays.

The target age group is divided under three categories:

- Birth to 6 weeks: Babies born at public health facilities or at home
- 6 weeks to 6 years: Pre-school children in rural areas and urban slums
- 6 to 18 years: School children enrolled in Class I to Class XII in government and government-aided schools

Children between 0 to 6 years will receive direct intervention services at the District Early Intervention Centre (DEIC). After this age, children receive services at existing public health facilities until the age of 18 years. Under this scheme, children are screened at both the community and facility levels. The facility-level screening is conducted at public health facilities like Primary Health Centres, Community Health Centres and District Hospitals, and will be conducted by existing manpower like Medical Officers, Staff Nurses, and Auxiliary Nurse Midwives (ANMs). The community-level screening is conducted by Mobile Health Teams at Anganwadi centres as well as government and government-aided schools.

Thus, child health screening and early intervention services under the National Rural Health Mission (NRHM), a sub-mission of the NHM, envisage covering 30 identified health conditions for early detection and free treatment and management. These include Down's Syndrome, anaemia, goitre and club foot.

JANANI SHISHU SURAKSHA KARYAKARAM (JSSK)

Launched in June 2011 by the Ministry of Health and Family Welfare (MoHFW), JSSK is an initiative that provides services for pregnant women as well as for sick newborn children up to 30 days after birth. This provision for the newborn children includes access to treatment, medication and diagnosis free of cost, particularly helping children with disabilities.[28]

[28]Source: Janani Shishu Suraksha Karyakaram (JSSK), National Health Portal of India [Available at: https://www.nhp.gov.in/janani-shishu-suraksha-karyakaram-jssk_pg]

FACILITY BASED NEWBORN CARE (FBNC)

Another national initiative that focuses on early intervention for children with disabilities is Facility Based Newborn Care (FBNC). The initiative focuses on improving the health of newborn children after delivery. This is especially crucial for sick infants and those born with a low birth weight.[29]

SAHYOGI

A scheme set up by the National Trust under the aegis of the Ministry of Social Justice and Empowerment, Sahyogi aims at providing adequate and nurturing care for PwDs as well as their families who may require it. The scheme also aims at providing parents with training opportunities related to caregiving, directly benefitting those parents who have children with disabilities.[30]

NATIONAL PROGRAMME FOR PREVENTION & CONTROL OF DEAFNESS (NPPCD)

The National Sample Survey Office (NSSO) 2001 states that 291 people out of every one lakh of the population suffer from profound hearing loss. Furthermore, a large percentage comprises children between the ages of 0 to 14 years. Thus, the National Programme for Prevention & Control of Deafness (NPPCD) was initiated on a pilot basis in the year 2006-07 in 25 districts of 10 states and 1 union territory with the objective of early identification, diagnosis and treatment of ear problems responsible for hearing loss and deafness.

NPPCD is being implemented by the Ministry of Health and Family Welfare with the support of the Directorate General of Health Services. Its objective was to reduce deafness by 25% and reach out to 384 districts by the end of the 12th Five Year Plan. As on June 2016, NPPCD had expanded the program to 228 districts.[31] NPPCD works towards the following objectives:

- Prevention of avoidable hearing loss on account of disease or injury
- Early identification, diagnosis and treatment of ear problems responsible for hearing loss and deafness
- Medical rehabilitation of persons suffering with deafness across ages
- Provision of improved rehabilitation services to persons with deafness by strengthening the existing inter-sectoral linkages
- Development of institutional capacity for ear care services by providing support for equipment, material and training personnel

[29]Source: Facility Based Newborn Care, Department of Health & Family Welfare & Medical Education [Available at: http://cghealth.nic.in/dhs/content/FacilityBasedNewborncare.html]

[30]Source: Sahyogi (Care Associate Training Scheme), The National Trust [Available at: https://www.thenationaltrust.gov.in/content/scheme/sahyogi.php]

[31]Source: National Programme for Prevention and Control of Deafness, Directorate General of Health Services [Available at: https://dghs.gov.in/content/1362_3_NationalProgrammePreventionControl.aspx]

The NPPCD involves a threefold strategy of identification and intervention of persons with deafness, capacity building of service providers, and awareness generation to achieve its objectives. Among the programs various positive outcomes, over 335 screening camps were organised across districts with the support of NGOs by the end of the 11th Five Year Plan (2007-2012). As a part of the program, about 6380 hearing aids were fitted for free for select children up to the age of 15 years with free services for a period of one year.[32]

NATIONAL RURAL HEALTH MISSION (NRHM)

Under the National Rural Health Mission of India, every village in the country is to be provided with an ASHA worker, who is a trained community health activist. These women provide a range of services in villages, from immunisation, referral and escort services for Reproductive & Child Health (RCH) to counselling women on birth preparedness. Given how closely they are involved in maternal and child health, they are crucial to minimising the chances of birth disabilities in newborns as well as supporting children with special needs.[33]

JANANI SURAKSHA YOJANA (JSY)

A safe motherhood intervention program under the National Rural Health Mission (NRHM), Janani Suraksha Yojana focuses on reducing maternal and neo-natal mortality as well as post-delivery care. This focus on post-delivery care becomes crucial for aiding mothers who have children with disabilities.[34]

NATIONAL PROGRAMME FOR CONTROL OF BLINDNESS & VISUAL IMPAIRMENT (NPCB&VI)

NPCB&VI was launched in 1976 with the objective of reducing the prevalence of blindness to 0.3% by 2020. As per a rapid survey on avoidable blindness conducted under NPCB, it showed a reduction of 0.1% from 1.1% (2001-02) to 1% (2006-07). The main objectives of NPCB&VI are as follows:

- Reduce avoidable blindness through identification and treatment of curable blindness at primary, secondary and tertiary levels
- Develop and strengthen the strategy of NPCB for 'Eye Health for All' and prevention of visual impairment through provision of comprehensive universal eye care services and quality service delivery

[32]Source: About Accredited Social Health Activist (ASHA), National Health Mission

[33]Source: About Accredited Social Health Activist (ASHA), National Health Mission

[34]Source: Janani Suraksha Yojana (JSY), National Health Portal [Available at: https://www.nhp.gov.in/janani-suraksha-yojana-jsy-_pg]

- Strengthen and upgrade Regional Institutes of Ophthalmology (RIOs) to become centres of excellence in various subspecialties of ophthalmology
- Strengthen existing infrastructure facilities and develop additional human resources for providing high quality comprehensive eye care in all districts of the country
- Enhance community awareness on eye care and lay stress on preventive measures, increase and expand research for prevention of blindness and visual impairment
- Secure participation of voluntary organisations/private practitioners in delivering eye care

This initiative led to the setting up of Multipurpose District Mobile Ophthalmic Units in the district hospitals of States/Union Territories. It also laid emphasis on covering comprehensive eye care coverage (Diabetic Retinopathy, Glaucoma, Corneal Transplantation, Vitreo-Retinal Surgery, Treatment of Childhood Blindness including Retinopathy of prematurity), and distribution of free spectacles to old people suffering from presbyopia[35] to enable them to undertake near work. Furthermore, due emphasis has been provided to strengthen tertiary eye care centres by providing funds for modern ophthalmic equipment, setting up super speciality clinics for all major eye diseases, lining tele-ophthalmology centres at PHCs with super specialty eye hospitals, and developing networks of eye banks and eye donation centres linked with medical colleges and RIOs.

DISHA (EARLY INTERVENTION & SCHOOL READINESS SCHEME)

The scheme[36] is directed towards setting up Disha Centres for early intervention and ensuring school readiness of children in the age group of 0 to 10 years through therapies, training, and providing support to family members. The guidelines of the Disha Centres ensure day-care facilities for children with disabilities for at least 4 hours in a day along with age-specific activities. Further, the Centres are mandated to remain open for at least 21 days in a month. The minimum attendance required for a CwD is 20 days in a month.

[35]Presbyopia is the gradual loss of your eyes' ability to focus on nearby objects

[36]Source: Disha (Early Intervention and School Readiness Scheme), The National Trust [Available at: https://www.thenationaltrust.gov.in/content/scheme/disha.php]

The monitoring mechanism of the Disha Centres is based on Key Performance Indicators including PwD strength (total strength of PwD present in the Disha Centre), LIG-Non LIG Ratio (ratio of PwDs from lower income groups to non-lower income groups), PwD development (overall development graph of PwDs), PwD mainstreaming (helping PwDs to take admission in mainstream schools), and parents' counselling (counselling sessions for parents/guardians to take proper care of PwDs).

	DISHA	VIKAAS
AGE	0-10 years	Nearly 10 years
AIM	Therapies, training & caregiver support	Interpersonal, vocational services
DURATION	4 hours	6 hours
ATTENDANCE	20 days a month	15 days a month
KPIs	PwD strength PwD Development PwD Maintstreaming Parents' Counselling Low income group/ Nonlow income group ratio	PwD Development Gainful employment of PwDs Low income group/ Nonlow income group ratio

Fig 13: Overview of Disha and Vikaas Schemes

VIKAAS (DAY CARE SCHEME)

This is a day-care scheme primarily designed to expand the range of opportunities available to children with disabilities nearing the age of 10 years. This scheme is directed towards enhancing interpersonal and vocational skills of CwDs. Additionally, this scheme provides support services to parents of CwDs as well.[37]

[37]Source: Vikaas (Day Care), The National Trust [Available at: https://www.thenationaltrust.gov.in/content/scheme/vikaas.php]

7. BEST PRACTICES FROM INDIA & ABROAD

Sarthak's early intervention programs and resources were formulated in response to three key aspects – the needs and importance of the interventions (as seen in Chapter 5), the larger national context within which the interventions function (as seen in Chapter 6) as well as best practices pertaining to early intervention from India and abroad. This chapter seeks to delineate and describe some of these best practices across countries as well as organisations.

7.1 INDIAN BEST PRACTICES: ORGANISATION CASE STUDIES

UMMEED LEARNING CENTRE, NEW DELHI

Ummeed runs an "Early Childhood Intervention Center" (EIC) which seeks to prepare CwDs between the ages of 2 and 5 to enter mainstream schooling. The project was born from the realisation that many children were unable to get into regular playschools and so were missing out on early intervention. The EIC is headed by an occupational therapist and run by regular school teachers as well as a Child Development Aide.

The EIC uses a child-centred play-way philosophy to teach children through play, songs and stories. It also involves active involvement of the parents in order for them to replicate such activities at home as well. Additionally, in order to become a model for other early childhood development intervention programs, Ummeed's EIC teachers visit and train teachers from several city preschools on including CwDs in their classrooms.

Source: Early Childhood Intervention Center, Ummeed [Available at: https://ummeed.org/early-intervention-center]

AMAR JYOTHI CHARITABLE TRUST, NEW DELHI

Amar Jyoti Chartiable Trust started Amar Jyoti School in 1981 with 30 children. The school educates children with and without disability in equal numbers. Today, the institution caters to over 500 children in New Delhi and 300 children in Gwalior. Amongst the institution's key activities is the provision of preparatory classes for the inclusion of children with developmental, hearing and visual disabilities as well as those with multiple disabilities.

Source: Amar Jyoti Charitable Trust Official Website [Available at: https://amarjyotirehab.org]

THE PONTY CHADHA FOUNDATION, NOIDA

The Foundation provides rehabilitation and intervention services for PwDs, specifically working with children with intellectual impairment, cerebral palsy, ASD, hearing impairments as well as multiple disabilities. The Foundation runs the Mata Bhagwanti Chadha Niketan (MBCN), a school for CwDs. Services provided by the Foundation include:

- Early intervention therapy imparting basic life skills to children between ages 3 and 6
- Speech therapy using the latest software to enable children to develop normal speech habits and work on verbal communication as well as fluency of speech
- Individual Education Programme (IEP) customised for children to develop their social, motor, academic and communication skills
- Occupational therapy to enable the children to be as independent as possible
- Physical therapy to enable children with physical disabilities to reach their optimal functional abilities

Source: Areas of Work, The Ponty Chadha Foundation

NATIONAL INSTITUTE OF SPEECH & HEARING, MYSURU

Focusing on people with speech and hearing disabilities, NISH has an Early Intervention Centre. The Centre started a "Parent Support Group" through which parents who have helped their hearing impaired children overcome language acquisition barriers guide and help other parents. Furthermore, hearing impaired children who study in NISH receive assistance and guidance from school experts directly, enabling them to overcome the disability with training and practice.

Source: Early Intervention, National Institute of Speech and Hearing [Available at: nish.ac.in]

SWAMI VIVEKANAND NATIONAL INSTITUTE OF REHABILITATION TRAINING AND RESEARCH (SVNIRTAR), CUTTACK

One of the major departments under SVNIRTAR is the Department of Occupational Therapy (OT) which provides necessary intervention services to the Institute's clients. These interventions focus on teaching requisite skills and educating the client and/or family on the importance of performance of daily activities.

This OT department has two major components: academic activities and clinical activities. While academic activities focus on long-term and short-term courses, clinical activities include the assessment, planning and provision of OT services to different clients.

Source: Department of Occupational Therapy, Swami Vivekanand National Institute of Rehabilitation Training and Research [Available at: http://www.svnirtar.nic.in/?q=node/37]

BEHAVIOUR MOMENTUM INDIA, GURUGRAM

Behaviour Momentum India is an organisation which provides intervention services for children with autism, Asperger's Syndrome and ADHD based on Applied Behaviour Analysis (ABA). Their intervention programs include:

- Early Intensive Behavioural Intervention (EIBI), Intensive Behavioural Intervention (IBI) and Intensive Language Program (ILP) which focus on teaching skills including communication, imitation, social interaction, visual performance self-care, and academic readiness to children
- Intervention Support Program (ISP) which focuses specifically on communication and language
- Academic Support Program aimed at teaching academic targets to children

Source: Intervention, Behaviour Momentum India [Available at: https://behaviormomentum.com/services/intervention/]

THAKUR HARI PRASAD INSTITUTE OF RESEARCH AND REHABILITATION FOR THE MENTALLY HANDICAPPED (THPI), HYDERABAD

Thakur Hari Prasad Institute (THPI) works on the rehabilitation of persons with intellectual disability who require multidisciplinary interventions to become as independent as possible. Given that the initial years are critical for such interventions, THPI focuses specially on an Early Intervention Program through which parents are sensitised.

This intervention program looks at identifying and evaluating developmental delays in infants and toddlers between 0 and 3 years of age. Thus, it can address developmental delays in children through appropriate interventions including sensory integration/nerve stimulation, cognitive therapy, and so on. A family-centred program, this involves the parent as a co-therapist to support nurturing the child's development in a natural environment to the extent possible with measurable outcomes.

Source: Early Intervention, Thakur Hari Prasad Institute [Available at: http://www.thpi.in/earlyinter.html]

7.2 GLOBAL BEST PRACTICES: COUNTRY CASE STUDIES

MALTA

The Child Development and Assessment Unit (CDAU) in Malta offers medical assessments and therapy to all children who are referred to the Unit from birth to 6 years of age. Such referrals come from baby clinics, doctors or speech therapists who are usually the first therapists to work with children if there are developmental delays in speech.

The children at CDAU are referred for different difficulties and disabilities including learning difficulties, ADHD, cerebral palsy and Down's Syndrome among others. The therapies or interventions undertaken at the Unit include occupational therapy and the therapists work with the children's family members, teachers and with other professionals for a holistic approach to early intervention.

At CDAU, the families of the children are at the centre of the services provided by child care facilities. At the kindergarten level, the family is also involved in the setting up and implementation of the child's Individual Educational Program (IEP) if the child has been identified as requiring extra support in class.

Thus, by ensuring that parents and their children get support at an early age, the CDAU's intervention services have been instrumental for the further positive development of the children who come to the Unit.

Source: Early Childhood Intervention Progress and Developments (2005-2010), EADSNE | Child Development Assessment Unit, Health Department (Govt. of Malta) | Early Childhood Intervention Project Update, Country Report-Malta, 2009

GREECE

ELEPAP-Rehabilitation for The Disabled is a non-profit and non-governmental charity organisation in Greece. Since 1937, the organisation has been working on rehabilitation of children with different physical disabilities as well as those with sensory, cognitive and speech problems from birth till they are 16 years of age. Thus, ELEPAP offers diagnosis, therapy, counselling, education as well as vocational training. It supports children with disabilities as well as their families, enabling them to develop through their therapies and programs.

ELEPAP's services are designed to promote the dual goals of enhancing potential capabilities of each child as well as providing psychosocial support to the families. As a result of the intervention strategies undertaken at ELEPAP, a significant number of children have overcome their disabilities. Furthermore, many children have been assisted to enhance motor functioning, communication abilities and self-esteem, reaching their full potential surpassing their own goals and expectations.

The organisation has so far impacted more than 1,00,000 children and their families enabling them to lead healthier and happier lives.

Source: ELEPAP-Rehabilitation for the Disabled, Global Sustain

GERMANY

The National Centre for Early Aid (Nationales Zentrum Frühe Hilfen) was established in Germany in the year 2007. The Centre aims at developing a system to detect children at risk at the earliest to then provide necessary intervention services. Furthermore, the Centre supports families and strengthens networking between different medical, educational and social institutions in early years. Finally, the Centre also aids research in early childhood intervention.

Source: Early Childhood Intervention Progress and Developments (2005-2010), EADSNE

ICELAND

The State Diagnostic and Counselling Centre (SDCC) in Iceland was established with the mission to ensure that children and adolescents with developmental disorders receive diagnoses as well as have access to counselling and resources.

The Centre does this by providing early intervention and multidisciplinary assessments. They also educate parents and professionals about children's disabilities and main treatment methods. Further, the staff participate in clinical research and various projects in the field of childhood disabilities in cooperation with local and international teams.

Source: State Diagnostic and Counselling Centre [Available at: https://www.greining.is/is/tungumal/english]

7.3 GLOBAL BEST PRACTICES: EARLY INTERVENTION FOR CHILDREN WITH DISABILITIES

SANGATH, PAKISTAN & INDIA

Sangath is a parent-mediated intervention program for Autism Spectrum Disorders (ASD) in South Asia Plus. The objective of the program is to develop an early detection methodology and intervention services for children with autism in Pakistan and India.

Sangath focuses on addressing two crucial needs of families who have children with ASD: (i) lack of early identification which then delays intervention and treatment and (ii) lack of access to interventions that are evidence-based due to various barriers. Thus, this program comprises a package to enhance early detection of ASD and another holistic package which focuses on care for families of children on the spectrum, called the "Treatment Package". This "Treatment Package" is aimed at addressing the core communication challenges of children on the spectrum. The activities in the package focus on various objectives including establishing shared attention during play, creating harmonious interactions through language, enhanced understanding of language, establishing a routine, and increasing other functions of communication.

This program has enabled children on the spectrum to enhance their communication, thereby reducing severity of the symptoms.

Source: Examples of early intervention programmes for children with developmental disabilities, Future Learn

EARLY CHILDHOOD INTERVENTION, USA

ECI is a support and educational system in the United States for children who have developmental delays or disabilities as well as those who are at high risk of abuse/neglect. Intervention services under ECI include evaluation and assessment, family-centred services and case management apart from many others. These services are provided by a team of experts including early intervention experts, speech and language pathologists, physical and occupational therapists, social workers, registered nurses, counsellors and psychologists.

Source: Early Childhood Intervention Services, Texas Health and Human Services

ABAaNa, UGANDA

The ABAaNA Early Intervention Programme is aimed at infants who are at high risk of developmental disability. This program has been adapted from another program called 'Getting to Know Cerebral Palsy' for parents who have children over two years of age. The program provides participatory, community-based interventions through groups of 6–8 caregivers in the community. These groups are facilitated by mothers who have older children with neurodisability, making them 'expert mothers'. Modules are also developed in partnership with speech and language therapists as well as physiotherapists.

Source: Kohli-Lynch, Maya; Tann, Cally J. & Ellis, Matthew E. (2019) "Early Intervention for Children at High Risk of Developmental Disability in Low- and Middle-Income Countries: A Narrative Review."

8. SARTHAK & EARLY INTERVENTION

8.1 SARTHAK'S STRATEGIES & SERVICES

Drawing from the best practices from India and abroad and responding to the specific socio-legal context of today, Sarthak works extensively to address the early intervention needs for India's CwDs. Established in the year 2014, Sarthak Antakshep Kendra has since grown to be an important centre for rehabilitating CwDs from birth to 14 years of age. Over the years, the Centre has been supported by corporates including Tech Mahindra, Crocs, Kotak Bank and Info Edge.

Before the child can be assessed and early intervention can begin, the Sarthak team works to mobilise parents and enrol CwDs in the intervention program. This is enabled through multiple strategies including:

- Community mobilisation through door-to-door visits to identify and reach out to CwDs and their families
- Referrals by hospitals and medical practitioners to ensure that those in need of early intervention services are aware of Sarthak
- Social media and online marketing to promote Sarthak's early intervention centres and their services

As the first step, the Sarthak team collects the child's name, age, concern, details of the parents and contact information. Following this, the parents are contacted for counselling and registration, either online or offline.

At Sarthak, every child is assessed by a multidisciplinary team including physiotherapists, occupational therapists, speech pathologists and psychologists. Following this assessment, intervention services are planned and provided. These services are available to children with neurological problems, birth defects, metabolic disorders as well as genetic disorders like cerebral palsy, Down's Syndrome, Autism, ADHD, Spina Bifida, Hydrocephalus and Epilepsy. So far, 2670 people have benefitted from Sarthak's early intervention services. (Refer to Annexure A for more details)

An important differentiating factor at Sarthak's centres is the involvement of parents. Since most therapies need to be repeated several times a day to ensure effectiveness, the team at Sarthak trains the parents and sensitises them on the needs of the child. Once parents are trained under the supervision of experts, they can assist their children within the comfort of their homes. Each personalised plan involves a combination of various interventions. Some of the most important strategies are discussed here.

COUNSELLING

Counselling for parents of CwDs is an ongoing process. Parents often struggle with both acceptance as well as the social stigma associated with disability. In order to address these stressors effectively, parents are given counselling and guided on how to treat CwDs equally. They are taught to focus on the child's abilities and are equipped with coping strategies and techniques to ensure their own health. Counselling involves equipping parents with a detailed understanding of their child's disability, associated concerns, ways to address them and assistive devices. Parents are also sensitised about the need for early intervention, the different therapies available and the many activities that could support their child's development. Sarthak's early intervention centres provide continuous handholding and support to parents through regular interaction sessions as well.

MANAGEMENT INFORMATION SYSTEM (MIS)

Sarthak utilises a robust internal MIS in order to facilitate efficient database management of beneficiaries. Through this system, the team is able to maintain records to track progress of children across centres and modify the intervention plan as required. The MIS records data throughout the lifecycle of a child's interaction with Sarthak including mobilisation, recording case history, diagnosis, intervention and therapy.

INDIA DISABILITY EMPOWERMENT ALLIANCE (IDEA) INITIATIVE

Sarthak hosts the India Disability Empowerment Alliance (IDEA) in order to connect with other NGOs working in the disability sector. The Alliance seeks to improve the sustainability and scalability of smaller NGOs in an effort to ultimately impact the larger disability community. This is done through various areas of capacity building including Strategy Monitoring & Evaluation, Fundraising and Human Resources Program Standardisation, and Marketing and Governance. So far, the organisation has collaborated with more than 200 NGOs, many of whom also work in early intervention. These organisations and their services are also promoted via CapSarathi.

DIGITAL SOLUTIONS

Sarthak offers various digital solutions which have become increasingly relevant during the COVID-19 pandemic. These solutions allow children to access early intervention services even when physical mobility is limited. Through these innovations, the Sarthak team has also been able to grow their footprint, ensuring more children across the country benefit from high-quality early intervention without being limited by geography. These solutions have become particularly important in the face of the COVID-19 pandemic. Sarthak's key digital solutions are as follows:

CapSarathi Mobile App: The CapSarathi mobile app is a joint initiative by Sarthak and Capgemini. This app was designed as a solution to reach out to parents, raise awareness on issues related to CwDs as well as provide them with the necessary information and support they require as caregivers. Through this app, Sarthak hopes to reach out to CwDs and their families across geographies, age groups and disability categories.

Direct beneficiaries of the app currently include PwDs as well as parents of CwDs whereas indirect beneficiaries include public and private sector service providers, policy makers, government officials, social workers, NGOs, academic institutes/social work students and corporates.

With over 13,000 users as of April 2022, the app is available on Google Play Store and the Apple Store. The app is geared to grow in user base as well as volume of information hosted in the future.[38]

Online Therapy, Progress Tracking & Parental Counselling: Launched with the outbreak of COVID-19, online therapies focus on home-based activities for parents to undertake under the guidance of therapists. It enables continuity of intervention even at times when physical access to therapy is limited. The online model also tracks progress of children against defined milestones, helping therapists achieve goals more effectively.

Along with its online therapy support, Sarthak team also equips parents with the required understanding and counsels them to deal with the stress associated with raising a child with disabilities. Sarthak also organises parent interaction sessions regularly to provide parents with an environment to share their experiences and learn from each other's journey. A Parent Interaction Forum is also available on the CapSarathi platform.[39]

GyanSarathi – E-Learning Management System: Another digital solution, GyanSarathi – Sarthak's E-LMS is expected to launch in 2022. It is an automated system that will provide end-to-end solutions across screening of development concerns, assessments, therapies, progress review, and parental guidance for home-based activities as well as parent interaction groups. The platform will allow therapists to intervene and update auto-suggested intervention plans with individualised suggestions as required.

The objective of the E-LMS is to design and develop a custom learning management system for PwDs in order to provide learning opportunities through the online medium. The solution for achieving this objective entails a cloud-based web application along with a mobile application. These platforms seek to cater to multiple stakeholders including learners, coaches, administration and the general public.

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[38]To access CapSarathi, visit https://sarthakindia.org/Capsarathi.php

[39]Sarthak's Parent Interaction Forum is designed for parents of CwDs to enhance their knowledge about disabilities. Parents can access audio-visual and textual resources on the forum available at www.capsarathi.com. Once parents log in, they will be able to access the Forum under the 'Our Services' tab.

8.2 SARTHAK'S PROCESS

Sarthak is committed to providing high-quality, holistic services to the PwD community and the strategies described above play an important role in enabling this. Beyond these strategies, quality in the early intervention program in specific is enabled by a multistakeholder approach that involves paediatricians, speech therapists, audiologists, psychologists, occupational therapists, physiotherapists, special education consultants, family support workers, and inclusion support workers. Apart from these stakeholders, the organisation also works closely with other changemakers.

Anganwadi workers: Sarthak conducts workshops with Anganwadi workers to build awareness on disability. This is crucial given how closely they work with mothers and children. Together with ASHA workers under the National Rural Health Mission, Anganwadi workers are crucial for preventing and managing disabilities through early detection of developmental delays across milestones including height, weight and MUAC.

Parents: Workshops are conducted at regular intervals to sensitise parents on topics related to child development, provide them with counselling, update them on the progress of their child, and share guidelines for home-based activities and therapy. Professionals are invited to make the sessions informative and interactive.

General community: Sarthak organises awareness camps with the wider society to spread awareness about the services provided and maximise the number of beneficiaries who could avail of Sarthak's interventions.

Medical practitioners: Through Continuous Medical Education (CME) workshops, Sarthak works with medical practitioners to enable a more nuanced understanding of early intervention and its effects on children.

Sarthak's early intervention services are largely implemented through the organisation's dedicated centres – two in Delhi and Ghaziabad. These centres are equipped with the resources and infrastructure needed to provide services to CwDs. (For a detailed list of infrastructure available, refer Annexure B.)

Apart from the infrastructure, the centres also have the necessary staff including a psychologist, speech therapist, special educator and occupational therapist. Thus, with the internal resources in collaboration with external stakeholders, Sarthak adopts a step-by-step process to ensure individualised, structured, organised, regular and predictable support towards the overall development of CwDs.

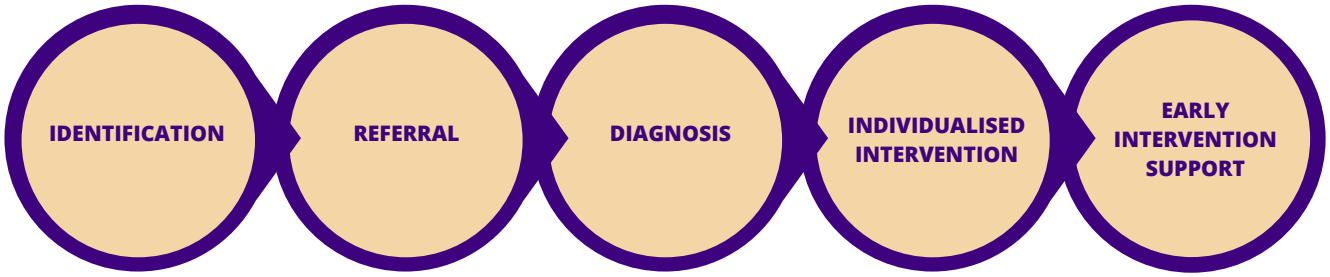

Fig 14: Sarthak's Early Intervention Process

Step 1: Identification: Following mobilisation of CwDs through community visits or referrals from medical staff, the first step starts with identifying infants or children with higher risk of developing a disability. It also involves identifying young children showing early signs of social, emotional or behavioural problems such as withdrawal and fearful behaviour, anxiety, distress, aggression or disruptive behaviour.

Step 2: Referral: This step involves referring the child and family to specialist services for assessment of development, behaviour and overall wellbeing of the child. When new children visit Sarthak's early intervention centre or Antakshep Kendra, a comprehensive assessment is done. Such an assessment helps understand the current level of a child's abilities, identify what should be taught next, and address any guidance and counselling needs of the parents. Furthermore, such an assessment is helpful in framing a therapy routine for the child. In case of concerns associated with a child's development or behaviour, families could consult a general practitioner for initial assessment.

Step 3: Diagnosis: Following referrals, the third step is diagnosis. The early intervention service provider diagnoses the child after gaining an in-depth understanding of the factors affecting the child and the family. Such a diagnosis involves the use of various assessment tools.

Step 4: Individualised Early Intervention Plan: This stage involves drafting an intervention structure with a timeline to support positive development outcomes of the child. Here, long-term (quarterly) goals and short-term (monthly) goals are identified for every individual child. These are then reviewed on a monthly basis. This review informs the next cycle of goal-setting for the child.

Step 5: Early Intervention Support: Finally, treatment and support services are provided in accordance to the individualised intervention plan of the child. These interventions involve working with occupational therapists, speech therapists, special educators and psychologists.

This multi-step and multi-stakeholder process is well supported by Sarthak's physical infrastructure at the Antakshep Kendra. These physical spaces enable the team to provide intervention support in physical, cognitive, social-emotional, speech and language, and adaptive development.

Sarthak has dedicated physical spaces for Psychological Testing, Occupational Therapy, Speech Therapy, Special Education as well as for the office area and the reception. Each of these spaces as well as the various assessments require a range of resources and props which are also available at the Centres. These include crash pads, bouncing balls, balance beams, vibrator brushes and stacking rings. (Refer to Annexure B for details on required resources and props.)

OCCUPATIONAL THERAPY

Requires resources such as balance beam for coordination, ball pool for tactile training, soft toys to enhance touch, swings to improve sensory skills and wedges to assist positioning

SPEECH THERAPY

Requires resources such as bell for sound orientation, candles for air control, mirrors for imitation, drums for auditory training, straws to improve sucking and xylophone to improve focus

SPECIAL EDUCATION ROOM

Requires resources such as blackboard for writing practice, computers for digital training, stickers for rewards, story books for moral education and stationery

SIMULATION ROOM

Requires resources such as disco lights to get child's attention, hammock for positioning, hydropool to increase flexibility and sand pool for sensory training

OFFICE AREA

Requires resources such as books and newspapers to provide visitors with latest information as well as CCTV to ensure safety of children

Fig 15: Resources Required at Antakshep Kendra

Apart from the physical infrastructure, the Sarthak process draws from multiple standardised assessment tools. These tools allow the team to create intervention plans informed by data. Further, these tools offer objective methods of monitoring the child's progress. Each child goes through anthropometry procedures[40] to assess weight and height of infants and children before undergoing psychological assessments. Some of the key assessment tools are as follows:

[40]It refers to the systematic measurement of the physical properties of the human body.

Developmental Screening Test: To identify developmental problems among children by measuring developmental age of the child with respect to chronological age

Vineland Social Maturity Scale: To measure the differential social capacities of an individual and provide an estimate of Social Age (SA) and Social Quotient (SQ)

Developmental Assessment Scale for Indian Infants (DASII): To assess Developmental Quotient (DQ) of infants between the age of 3 months and 2.5 years based on motor and mental development indicators

Malin's Intelligence Scale for Indian Children (MISIC): To assess the Intelligence Quotient (IQ) and cognitive abilities of a child between 6 to 15 years of age

Indian Scale for Assessment of Autism (ISAA): To assess symptoms and severity of autism in a child ranging across mild, moderate or severe

Childhood Autism Rating Scale (CARS): To help in diagnosis of autism in children

NIMHANS Battery of Learning Disability: To diagnose learning disabilities

Diagnostic Test of Learning Disability (DTLD): To diagnose areas of learning disabilities in a child

Attention Deficit Hyperactivity Disorder (ADHD) Rating Scale: To assess presence and extent of ADHD in children as well as symptoms (including inattention, hyperactivity and impulsivity)

Fig 16: Assessment Measures at Sarthak's Early Intervention Centres

8.3 THERAPIES AT SARTHAK

Following the assessment, diagnosis and creation of an individualised plan, CwDs benefit from various therapies at the Antakshep Kendra. Therapists track their progress regularly and parents are trained to support the children at home. While most of these therapies are used across disabilities, the focus areas differ across disabilities.

Beginning therapy as early as possible is known to help improve and better manage disabilities. Hence, Sarthak's main emphasis is on making parents understand the importance of therapy for children with developmental disabilities. In the absence of such interventions, children grow increasingly dependent on others and may adopt problematic behaviours. With early intervention and therapy, many of these risks can be avoided.

Sarthak's therapeutic interventions are aligned to international standards as well as best practices in India and abroad. Children benefit from high quality infrastructure as well as access to trained therapists. (For details on available infrastructure, refer Annexure B.)

PHYSICAL & OCCUPATIONAL THERAPY

Physical and occupational therapy refer to the therapeutic use of everyday life activities (occupations) with individuals or groups for the purpose of enhancing or enabling participation in roles, habits, and routines at home, school, workplace, community, and other settings. It involves improving gross and fine motor skills, balance, coordination, hyperactivity, sensory issues, strength and endurance. Gross motor skills involve larger muscles of the body like rolling, crawling, walking, running and jumping. Fine motor skills involve smaller muscles like the ability to hold a spoon or pick up a toy.

Occupational therapy practitioners use their knowledge of the transactional relationship between the person and his/her occupation and context to design intervention plans. Such plans facilitate change or growth in behaviours (body functions, body structures) and skills (motor, process and social interaction) needed for successful participation in larger society. Occupational therapy mainly helps in improving skills and reducing tightness, tone, and spasticity of muscles, apart from dealing with sensory issues as well. Some basic OT activities are:

- Activities to improve fine motor skills so the child can grasp and release toys and develop good handwriting skills
- Activities to address hand-eye coordination to improve playing (hitting a target/ball) and school skills (copying from blackboard)
- For a child with severe developmental delays, activities to make them learn basic tasks such as bathing, getting dressed, brushing and feeding themselves
- For a child with behavioural disorders, activities to help maintain positive behaviours in all environments
- For a child with physical disabilities, activities to learn coordination skills needed to feed themselves, and write legibly and in good speed
- For a child with sensory and attention issues, activities to improve focus and social skills
- Evaluations to understand need for specialised equipment such as wheelchairs, splints, dressing devices or communication skills

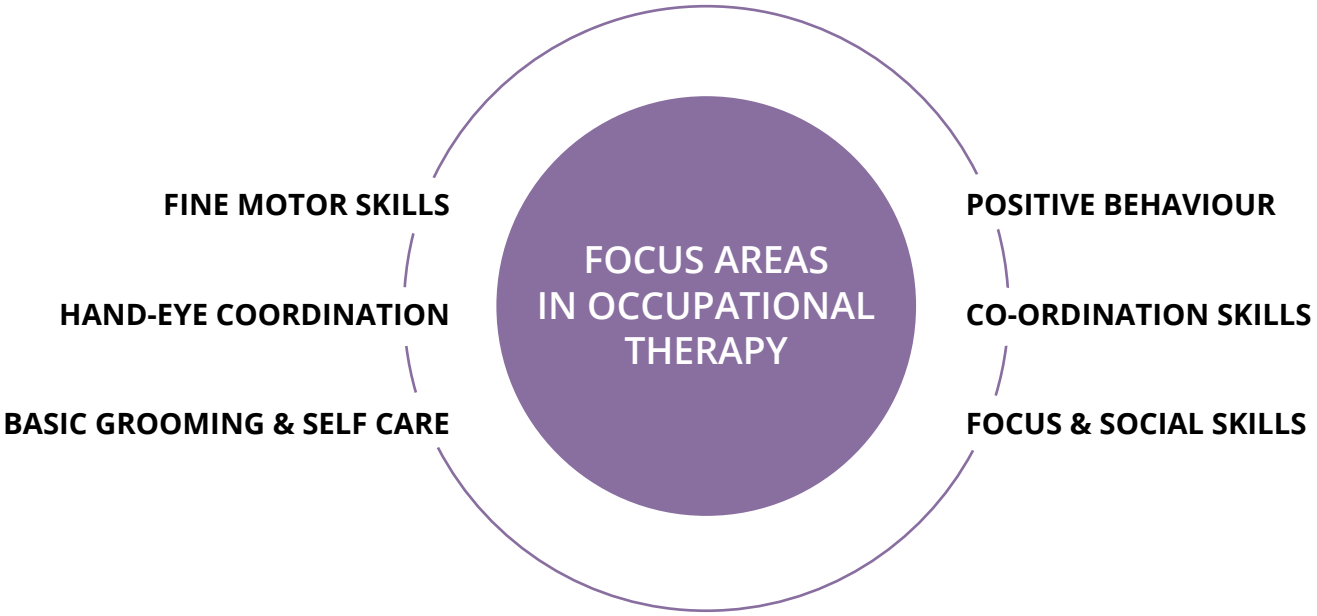

Fig 17: Focus Areas in Occupational Therapy

Physical and occupational therapy at Sarthak include activities such as support for recreation, play and leisure, adaptive play, aquatic (water) therapy, balance board for muscle strengthening, bolster for balancing while sitting, bubbles for visual attention and so on.

Physical and occupational therapy focus on decreasing hyperactivity for children with ADHD, reducing sensory issues for those on the autism spectrum, and achieving developmental milestones for children with cerebral palsy. In the case of children with Down's Syndrome, physical and occupational therapy looks to strengthen muscle tone while it focuses on achieving delayed milestones in case of intellectual disability and improving attention in case of learning disability.

SPEECH AND LANGUAGE THERAPY

Speech therapy seeks to enable children's verbal communication. All children who need speech therapy have different concerns, and therapy is planned as per each child's requirements. Some of the key areas of focus for speech therapy include:

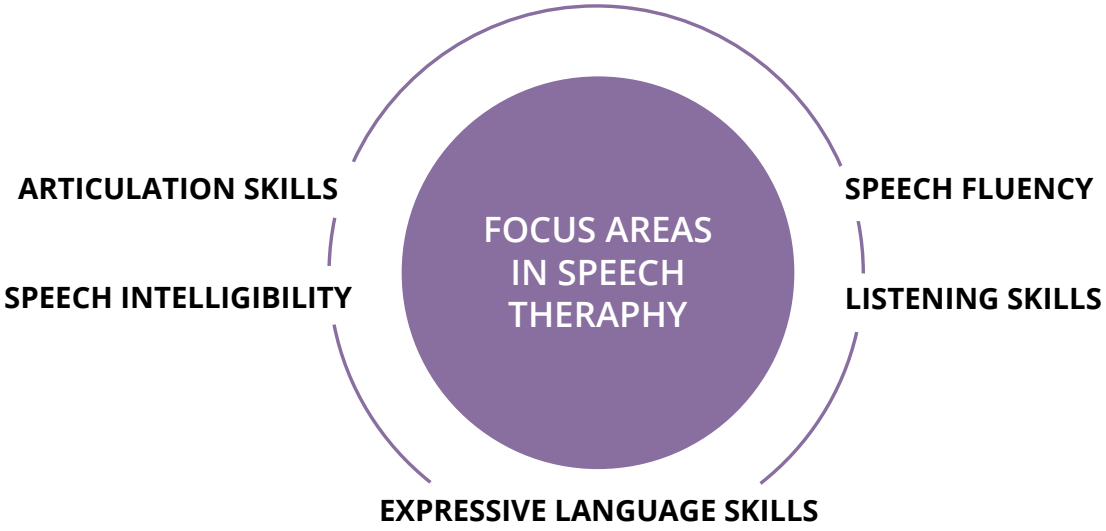

Fig 18: Focus Areas in Speech Therapy

Articulation Skills: It works on a child's physical ability to move the tongue, lips, jaw and palate (known as articulators) to produce individual speech sounds.

Speech Intelligibility: It refers to how well people can understand a child's speech. If articulation skills are not good, intelligibility is decreased in comparison to other children of the same age.

Expressive Language Skills: Speech language pathologists help the child learn new words and put them together to form phrases and sentences (semantics and syntax).

Receptive Language/Listening Skills: Receptive language or listening skills includes improving the child's ability to listen and understand language. Here, a child is taught new vocabulary and how to use that knowledge to follow directions, answer questions and participate in simple conversations with others.

Speech Fluency: This addresses concerns associated with stuttering or having too many breaks in the flow of speech.

Children who are hearing impaired and are using hearing aids need regular speech therapy. This ensures that their habit of lip reading does not develop as relying on lip reading alone is based largely on guesswork and is insufficient for good communication. Children who have undergone cochlear implant surgeries also usually need speech therapy to help recognise sounds and communicate as early as possible. Speech therapy at Sarthak focuses on developing sound awareness for those with ADHD, intellectual disability, Down's Syndrome and learning disability. It seeks to improve oro-facial muscles for those on the autism spectrum, develop speech for children with cerebral palsy, and develop auditory skills in case of hearing impairment.

The main overall objective of speech therapy is to improve communication. Some of the specific objectives of this therapy might include:

- Improving coordination of speech muscles through strengthening and coordination exercises, sound repetition, and imitation
- Improving communication between the brain and the body through visual and auditory aids such as mirrors and tape recorders
- Improving fluency through breathing exercises
- Enhancing language learning through language stimulation and encouraging the use of that language through positive reinforcement
- Helping a child learn alternative ways to communicate, including gestures, signing or augmentative communication devices

WHY DO SOME CHILDREN NEED SPEECH THERAPY?

Speech Therapy is an important aspect of early intervention for multiple intellectual and developmental disbilities including but not limited to:

- HEARING IMPAIRMENTS
- WEAK ORAL MUSCLES
- COGNITIVE OR OTHER DEVELOPMETAL DELAYS
- CHRONIC HOARSENESS
- CLEFT LIP/ CLEFT PALATE
- AUTISM
- MOTOR PLANNING PROBLEMS
- ARTICULATION PROBLEMS
- FLUENCY DISORDERS
- RESPIRATORY PROBLEMS
- FEEDING/SWALLOWING DISORDERS
- TRAUMATIC BRAIN INJURY

Fig 18: Need for speech therapy

TECHNIQUES & STRATEGIES USED AT SARTHAK

Flash cards: Flash cards help children focus on the sounds that they find difficult. These cards allow for activities that could make therapy more entertaining. Therapists may also reward the children when done correctly. For example, a small piece of candy (chewable is good for strengthening jaw muscles) may be given to children after saying a certain number of sounds on the language cards correctly.

Mirror exercises: Many kids with articulation problems do not understand how to move their mouths to make sounds correctly. Speaking in front of a mirror can help children see how their mouth moves when they make particular sounds. Therapists may also articulate each sound slowly and correctly to model proper positioning for the child and demonstrate the differences in the mirror.

Blowing and breathing exercises: Blowing on whistles helps train mouth muscles to form shapes needed for producing particular sounds. Blowing activities also strengthen abdominal muscles and help children with cerebral palsy control breathing.

Language and word association: Speech therapists use pictures, books and objects to stimulate language development. While playing and talking with a child, for example, therapists model correct language and association patterns, prompting the child to build vocabulary and grammar skills

Fig 20: Techniques and Strategies Used in Speech Therapy

EARLY CHILDHOOD SPECIAL EDUCATION (ECSE)

ECSE refers to providing academic support to CwDs, particularly those who find it difficult to cope with mainstream education. This involves helping CwDs understand the content of their lessons as well as adopting different teaching methodologies that are better suited to their individual disabilities. Teaching strategies include starting with simple functions and ideas known to a child before moving on to complex concepts. The trainers also begin with concrete objects or ideas (such as hot, cold, apple, mango) before dealing with abstract concepts and ideas (such as truth, freedom, justice). ECSE also adopts a whole-to-parts approach under which the child is taught about, for example, full circles before learning half circles. This process is highly individualised for each CwD.

Fig 21: Principles of Special Education

Special education is characterised by a commitment to being measurable and testable, goal-directed, diagnostic and universal. The guiding principles of special education include the participation of the parents as well as the students. This system of education also adopts non-discriminatory identification and evaluation.

Special education at Sarthak focuses on the holistic development of a child's personality apart from enabling the child to be independent, adaptable and cognisant of the rights available to him/her. For some of the key objectives of special education, refer Figure 22.

KEY OBJECTIVES OF SPECIAL EDUCATION

- Overall personality development
- Familiarity with child's abilities
- Parental guidance
- Accessible education opportunities
- Independence of child
- Adjustment to environment
- Appropriate education, personal & vocational guidance
- Contribution to growth of nation
- Awareness of rights & facilities provided by government

Fig 22: Key Objectives of Special Education

BEHAVIOUR MODIFICATION

The goal of behavioural modification is to increase desirable behaviours in CwDs. The foundation of behaviour modification is defined by the A-B-C model:[41]

Antecedents: Root cause or triggering factor for the occurrence of the behaviour

Behaviour: Action or response of the child (intensity or duration)

Consequences: Result of the action

To enable behaviour modification, professionals including Sarthak adopt a multi-step approach. This approach involves:

Identification of problem behaviour: Collecting information about the problem behaviour from the teacher, parent or guardian

Defining target behaviour: Characterising behaviour in observable and measurable terms

Hierarchy of problematic behaviours: Prioritising behaviours in terms of severity on the basis of prime concerns

Selecting targets: Seeking behaviours which are most disturbing or unmanageable and can be understood by asking the parents, caretaker or teachers of the child

Behaviour recording: Recording when and how behaviours occur before preparing and implementing the behaviour modification program

[41] Source: ABC - Antecedent, Behaviour, Consequence, ThoughtCo

9. CASE STUDIES FROM SARTHAK

9.1 DEEPAK | ATTENTION DEFICIT HYPERACTIVITY DISORDER

Fig 23: Process of intervention at Sarthak

Attention Deficit Hyperactivity Disorder (ADHD) is a condition which includes hyperactivity, attention difficulty and impulsiveness. It results in an ongoing pattern of inattention and/or hyperactivity-impulsivity which interferes with the functioning or development of the child. Children with ADHD experience various types of symptoms including the following:

Inattention: This means that a person may have difficulty concentrating on tasks, sustaining focus, and staying organised. It is important to recognise that these problems are not rooted in a lack of comprehension or defiance.

Hyperactivity: This means that a person may seem to move constantly, including during situations when such behaviour is not appropriate. This movement often presents as fidgeting, tapping or talking excessively.

Impulsivity: This means that a person may act without thinking or have difficulty with self-control. It could also include a desire for immediate rewards or being unable to delay gratification. An impulsive person may make important decisions without thinking of long-term consequences.

Deepak is an 11-year-old child with ADHD from a middle-class family. He lives in a joint family and has three older sisters. His father works in the private sector while his mother is a housewife. The family largely communicates in Hindi.

Deepak was a full-term child born by normal vaginal delivery and weighed 2.5 kgs at birth. He did, however, have a delayed birth cry. His history reveals that he first developed seizures at age 8. At this point, his parents sought medical attention and the child was recommended continued medication.

Deepak was 8 years and 7 months old at the time of Sarthak's assessment and was diagnosed with ADHD (Attention Deficit Hyperactive Disorder) with mild intellectual disability. His nutritional consumption was normal and as the only son, he received a lot of attention from his family. His developmental age was 4 years and 8 months. Over two years, he had benefitted from multiple therapies at Sarthak's centre.

Name	Deepak
Chronological age at assessment	8 years 7 months
Developmental age at assessment	4 years 8 months
Diagnosis	Attention Deficit Hyperactivity Disorder with mild intellectual disability

When he was first presented at Sarthak, the team undertook a comprehensive assessment. This assessment revealed that Deepak had ADHD, exhibiting many symptoms on the checklist. His major areas of concern included the following:

- Does not sit in one place
- Poor attention span
- Does not follow commands
- Does not remember things
- Behavioural issues like hitting others, occasional stealing, stubbornness and excessive talkativeness
- Poor in academics

Following the assessments and identification of challenges, the Sarthak team formulated an individualised therapy plan for Deepak. This included goals for occupational therapy as well as special education. The goals were to reduce hyperactivity and increase attention span as well as ability to sit in one place. Relevant activities were mapped to these goals to enable Deepak's progress.

THERAPY	GOALS	ACTIVITY
OCCUPATIONAL THERAPY	First and foremost, a therapist worked on reducing the hyperactivity of the child so as to increase his sitting span and attention. Various occupational therapy-based activities were picked up for the purpose. The objectives of these activities were: - Reducing hyperactivity - Increasing sitting span - Improving attention span - Improving fine hand function - Making child follow one-step commands	The occupational therapist started with pressure activities to reduce hyperactivity concerns. These activities included: - Bedsheet wrapping - Ball pressure - Bear walk Thereafter, one-step instructions or commands were taught such as saying "goodbye" or "give me a bottle", and sitting down. Additionally, other activities were included to improve sitting span and attention span. These activities included: - Beads and thread - Clay activity - Sorting of *chana* and *rajma*
SPECIAL EDUCATION	Once the child's hyperactivity was controlled and attention span was increased, the special educator focused on supporting learning different concepts according to the age of the child. This included: - Command following in general - Identification & Writing of Alphabets (A to Z) and Numbers (1 to 50) - Identification & Writing of Hindi *Varnmala* - Colour Identification and Colouring - Counting activities	Various activities were conducted at the Sarthak Early Intervention Centre. Parents were also engaged and briefed to repeat the activities at home. The activities included: - Giving simple commands (come and sit, call mummy, give pencil box) - Books and worksheets for counting and alphabets - Using different colour beads and paper for colour identification - Dal pasting in given picture with different colours of dal - Colouring - Using different size of objects (for concepts of big and small)

When Deepak first came to Sarthak, he could not sit in one place and was hyperactive. His mother complained of his inability to follow instructions and his poor academic performance. He did not make eye contact, could not remember things and had a very short attention span.

After continuous therapy, Deepak's attention span improved. He can now sit in one place for longer and has improved with regards to following instructions. His hyperactivity has reduced and academics have improved as well. From his activities, he has been able to do dal pasting, colouring and sorting, follow 2-step commands, understand concepts of big and small, write the names of 5 basic fruits and vegetables as well as identify and write names of some colours. Additionally, he is able to do three-digit addition with carryover and two-digit subtraction sums with borrowing concept, comprehend before-after numeracy, and work on ascending order sums. In Hindi, he can read and write three-letter words like *kamal, naman,* and *bhagat*.

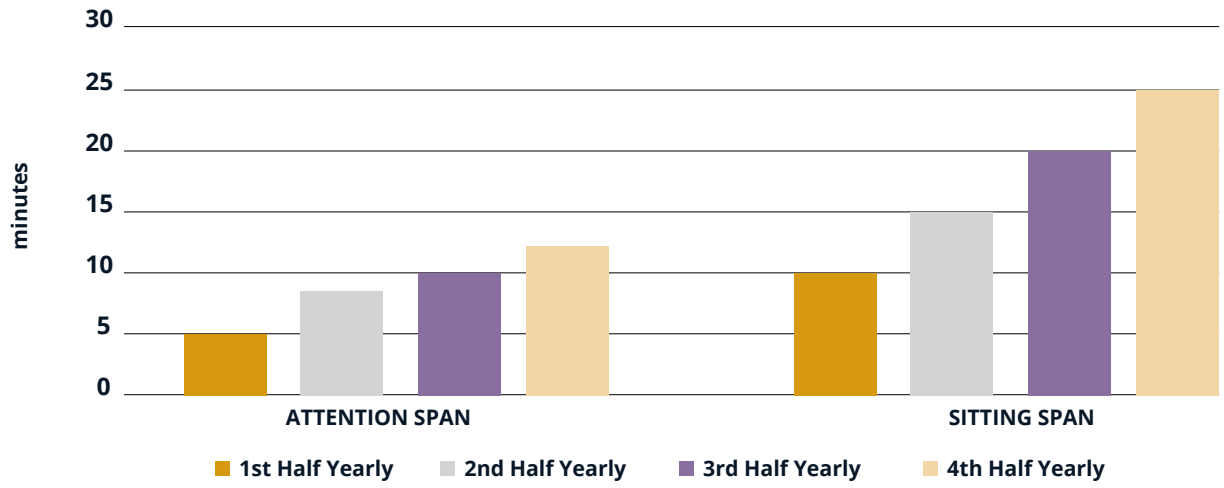

Fig 24: Deepak's Improvement

The figure above illustrates Deepak's improvements in attention span and sitting span post intervention. For instance, after six months of therapy, his attention span increased to 5 minutes whereas his sitting span increased to 10 minutes. Following two years of therapy, he was able to hold attention for over 10 minutes and sit for 25 minutes.

Deepak's family is very happy to see such vast improvement in their child and are grateful to Sarthak for the same. His mother is overwhelmed by the child's progress. She added that the constant guidance and support by the team at the Centre helped the parents overcome challenges related to Deepak and enabled them to understand his condition as well.

9.2 LAKSHIT | AUTISM SPECTRUM DISORDER

Lakshit was about 2 years old when he was suspected to be autistic. His father is in service and his mother is a housewife. He is a single child living in a nuclear family set-up. The family generally speaks in Hindi. His parents' marriage is a non-consanguineous one.

Autism Spectrum Disorder (ASD) is a developmental disorder that impairs the ability to communicate and interact. Autism impacts the nervous system of an individual and affects the overall cognitive, emotional, social and physical health of the person. Although it can be diagnosed at any age, it is said to be a developmental disorder as the symptoms usually appear in the first two years of a person's life.

The symptoms associated with ASD include the following:

- Difficulty in communication and social interactions
- Restricted interests
- Repetitive behaviours
- Other symptoms which affect the person's ability to function in school, work, etc.

Name	Lakshit
Chronological age at assessment	2 years
Developmental age at assessment	1 year 2 months
Diagnosis	Autism Spectrum Disorder

Lakshit's pre-natal history reveals that his mother had a history of typhoid, fever and cough during the third month of gestation due to which she was hospitalised for one week. She also experienced stress during the initial phase of her pregnancy. Lakshit was born full-term with a c-section delivery due to Meconium Aspiration Syndrome. When he was 7 days old, Lakshit had cough and fever, leading to hospitalisation for fifteen days. All his immunisations are on track and his nutritional consumption is good. Parents reported that he eats solid food like *roti, subzi, dal*, rice and fruits

When Lakshit first came to Sarthak, the team undertook a comprehensive assessment. This assessment revealed that Lakshit had mild developmental delay. His major areas of concern included the following:

- Difficulty in maintaining eye contact
- Poor sitting span
- Inability to play with other children in a group
- Difficulty with gross and fine motor skills
- Delayed speech
- Hyperactivity
- Poor attention span

Following the assessments and identification of challenges, the Sarthak team formulated an individualised therapy plan for Lakshit. He began receiving occupational therapy, speech therapy and special education sessions three days a week. The interventions were aimed at certain therapeutic goals for Lakshit including better linguistic skills and the ability to play and socialise while decreasing hyperactivity. Other goals for him included improving eye contact, sitting span and speech.

THERAPY	GOALS	ACTIVITY
OCCUPATIONAL THERAPY	Improving eye contact Improving sitting span Improving attention span	Laser light tracking Nose to nose pointing Clip activity Beads and thread activity

SPEECH THERAPY	Improving attention span Improving eye contact Improving oro-facial strengthening	Blowing bubbles Whistles Flashcards Chew tubes Vibrator brush Thread and bead activity Vocalisation Placement of articulators
SPECIAL EDUCATION	Improving gripping the pencil Improving scribbling Improving eye contact Improving attention span	Pencil holding Scribbling Colouring Nose to nose pointing

When Lakshit first came to Sarthak, he could not sit at one place, had poor eye contact, did not involve in group play, had poor speech and could not identify his parents in a picture. Additionally, his sitting span was poor and he could not hold a pencil or identify the names of fruits and body parts.

After a year of undergoing interventions facilitated by Sarthak, Lakshit is now able to sit in one place for 15-20 minutes, maintain eye contact and pay attention during activities. He is also able to vocalise vowel sounds, identify family members in a picture as well as identify the names of fruits and body parts. Additionally, he can now hold a pencil and scribble.

According to Lakshit's parents, "Lakshit is an autistic child and has been associated with Sarthak for the past 1 year. We have noticed a lot of changes in him during this period. The activities suggested by the therapist are easy and simple, and actually help the child learn through play."

9.3 TRIPTI | CEREBRAL PALSY

Cerebral Palsy (CP) is a group of permanent disorders in the development of movement and posture which cause activity limitation. It is the most common cause of physical disability in childhood. While some children have only a motor disorder, others have a range of problems and associated health issues. These disorders are attributed to non-progressive disturbances that occurred in the developing foetal or infant brain.

The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication and behaviour, by epilepsy, and/or by secondary musculoskeletal problems.

Name	Tripti
Chronological age at assessment	3 years 6 months
Developmental age at assessment	1 year 10 months
Diagnosis	Cerebral Palsy

Tripti's major complaints when she joined Sarthak included the following:

- Not being able to hold her neck
- Inability to roll or hold things in her hand
- Inability to sit without support
- Not able to chew food

Speech therapy was suggested to focus on improving her oro-motor functions such as sucking, chewing, eating and swallowing, reducing drooling as well as improving her speech.

THERAPY	GOALS	ACTIVITY
OCCUPATIONAL THERAPY	Achieving neck control Increasing muscle tone Improving core muscle strength	Prone on wedge Prone on therapy ball Joint compression Pull to sit Bridging & quadruped on bolster
SPEECH THERAPY	Improving facial muscle strength Reducing drooling Improving chewing	Facial massage Vibrator brush Finger tapping around the oral cavity Chew tube

Tripti has been associated with Sarthak for the past 9 months and attends occupational therapy and speech therapy. Her interventions were planned keeping in mind her specific musculoskeletal and neurological symptoms. She is now able to hold her neck and roll independently. Her muscle tone and strength have increased. She is also able to sit without support and hold small objects in her hand as well as look at family members when playing with them. Her drooling has reduced and she is now able to move her tongue in and out as well as chew *chapathi*.

Tripti's mother is happy to see the progress in her daughter. Every time her daughter learns something new, she is delighted. She makes sure to bring in Tripti regularly for therapies apart from attending online sessions. She is happy with Sarthak's services as the team is helping Tripti learn skills required to become functional and independent.

9.4 VARUN | DOWN'S SYNDROME

Down's Syndrome is a neurological disorder where a child's development is delayed. Children with Down's Syndrome require therapies to stimulate patterns of development. Although people with Down's Syndrome have some degree of developmental disability, it is usually mild to moderate. Such mental and social development delays may result in a child having the following symptoms:

- Impulsive behaviour
- Poor judgement
- Short attention spans
- Slow learning capabilities

Varun's birth history reveals that he was born pre-term (32 weeks) and suffered from delayed birth cry of approximately 6 minutes. He was kept in a Neonatal Intensive Care Unit (NICU) for 10-15 days due to delayed birth cry and low birth weight. Additionally, he had Patent Ductus Arteriosus (PDA, a congenital heart defect), and had to get operated when he was around 12 months old.

Name	Varun
Chronological age at assessment	4 years
Developmental age at assessment	2 years
Diagnosis	Down's Syndrome

After being diagnosed with Down's Syndrome, Varun's parents approached Sarthak along with their son. His major concerns at that time included:

- Not being able to speak
- Not being able to stand
- Inability to hold objects properly
- Academic concerns

THERAPY	GOALS	ACTIVITY
OCCUPATIONAL THERAPY	Improving muscle tone Improving muscle strength Improving hand functions Improving walking Improving attention span Improving balance and coordination	Joint compression Kicking a ball Blocks fixing Rings game Walking training Trampoline jumping Sitting for 2-3 minutes on vestibular board Thread and bead Rings activity
SPEECH THERAPY	Improving attention span Improving oro-facial strengthening Working on phonation duration Improving vocalisation of sounds Improving vocabulary	Thread and bead Rings activity Block fixing activity Vibrator brush Hand massage Sucking with straw Whistling activities Soap bubble Blowing candles Placement of articulators like a,e,o Flashcards of body parts
SPECIAL EDUCATION	Improving attention span Pencil holding Scribbling Joining dots Following one-step commands	Bead and thread Stacking cups Block fixing Using a grasper Taping on hand Standing or sleeping lines Worksheets

Initially, Varun would cry excessively during sessions but gradually began to show an interest in various therapy activities. During his association with Sarthak, a number of changes have been observed in him. He is now able to follow multi-step instructions, has an improved attention span and can sit at a stretch for 30-40 minutes, apart from completing tasks at hand.

Furthermore, his hand functions have improved and he has started walking and climbing stairs alternately. He is also able to speak 3-4 words/phrases and understand basic concepts such as fruits and vegetables. He now identifies numbers 1 to 50 apart from identifying family members and saying their names. Varun has also learnt to scribble, join dots (including standing line, sleeping line, slanting line and curving line), trace alphabets, and identify Hindi vowels.

Varun's parents are optimistic that the interventions will help their child learn. They say that when Varun first came to Sarthak, he did not know anything but after undergoing therapies, he has learnt many things. They are amazed at the journey so far and are delighted that Sarthak has helped them and their child in the best possible manner.

9.5 SUKHJOT KAUR | HEARING IMPAIRMENT

Sukhjot was a little over a year old when she was diagnosed with bilateral profound hearing impairment. When she first came to Sarthak, her chief complaints included the following:

- Poor understanding
- Not being able to express her thoughts in sentences
- Poor vocabulary

Name	Sukhjot Kaur
Chronological age at assessment	9 years 6 months
Developmental age at assessment	7 years 7 months
Diagnosis	Hearing Impairment

After an initial assessment and a speed evaluation, Sukhjot was enrolled for speech therapy to address her chief complaints. In keeping with due process at Sarthak, her therapy was formulated into an individualised plan.

THERAPY	GOALS	ACTIVITY
OCCUPATIONAL THERAPY	Improving auditory skills Improving vocabulary Working on phrases and sentences Improving reception and expression Improving socialisation	Auditory training Name calling Environmental sounds Flash cards Colour beads Rings Stacking cup Colour blocks Identification of fruits and vegetables Identification of animal sounds Identifying kitchen and bathroom sets Group activity Participating in play Storytelling activities

After 1 year and 8 months of undergoing continuous intervention therapies, Sukhjot was able to follow multi-step commands, had improved her auditory skills, and had a better vocabulary as well. She understood the concept of a calendar, and knew the names of fruits, vegetables, animals, colours and household things. She was also able to respond in sentences when she was asked something. She was able to greet people and say goodbye when she left the Sarthak Centre. Her social interactions with others increased and she played with her peer groups as well as participated in annual functions.

Sukhjot's parents add, "My daughter has hearing impairment and she received surgery for cochlear implant as well but it was difficult for us to bear the expenses of speech therapy and her progress stagnated after that. One of my friends referred us to Sarthak and I approached them for therapy. It has now been almost 2 years since we came here and the experience has been great. Sukhjot's vocabulary has improved and she has learnt many concepts. She speaks in small sentences which fills my heart with hope and makes me realise that learning has no boundary and only requires the right support."

9.6 AYUSH | LEARNING DISABILITY

Learning disabilities are disorders which affect various learning abilities of a person. Such a disability will affect an individual's ability to:

- Understand or use spoken or written language
- Do mathematical calculations
- Coordinate movements
- Direct attention

Such learning disabilities may occur in very young children. However, this disorder is usually recognised only when a child reaches school age.

Ayush was a full-term child and weighed approximately 3 kilograms at the time of birth. He was 8 years old when he was assessed and diagnosed with learning disability. At the time, his developmental age was 7 years and 11 months, indicating that had a normal range of intellectual functioning. He also maintained good nutritional consumption. His learning disability was understood as causing his issues in reading, understanding as well as mathematical calculations.

Name	Ayush
Chronological age at assessment	8 years
Developmental age at assessment	7 years 11 months
Diagnosis	Learning Disability

Ayush's major complaints thus included the following:

- Difficulty with comprehension
- Difficulty with mathematical calculations
- Difficulty with reading and motor issues
- Poor attention span
- Issues with concept understanding
- Academic concerns

Given his complaints and issues, an individualised therapy plan including occupational therapy and special education was created for him.

THERAPY	GOALS	ACTIVITY
OCCUPATIONAL THERAPY	Improving attention span, sitting, problem-solving, memory, fine motor coordination and gross motor skills Improving ability to follow commands Making the child follow two or multiple step command Differentiating between right and left	Catching and throwing a ball Dart game Sorting Puzzles Mazes Straight line walks and trampoline Multiple instructions Beads and thread activity Dal pasting Puzzles Backward jumping in a circle Tandem walking in a straight line Catching and throwing a ball Raising right leg and touching left leg
SPECIAL EDUCATION	Writing and learning the names of the months Learning opposite words Defining nouns and pronouns in English Understanding the concept of 3-digit multiplication sums and division Calculating perimeter and area of the rectangle Improving Hindi reading skills Learning tables 2 to 15 Understanding 3-digit division Calculating the perimeter and area of rectangles and squares Addition of fractions Writing answers for each chapter's questions	Worksheets Books Charts Assignments Blackboards and chalk

The therapy interventions enabled Ayush to improve his attention span, strengthen concept-building skills and enhance his motor skills. He is now more organised, has a better memory and is more responsible. Ayush's parents are happy to notice drastic improvements in their child. They added that that the early intervention therapies have benefitted Ayush and made him more organised, focused as well as responsible.

10. RECOMMENDATIONS & FUTURE PLANS

The need for early intervention is evident and interventions to address this need have grown over the last few years. However, there are significant gaps in the system that need to be addressed in order to ensure that all CwDs have access to the care, therapy and attention they need.

Data relating to CwDs is very limited. Both governmental as well as private sources of information are incomplete and rarely provide disaggregated data on individual disability categories. There is information regarding the number of CwDs and some data on education levels. However, disaggregated data for CwDs is almost negligible. This paucity of data is only aggravated when seeking information on children with specific disabilities, such as those with intellectual or developmental delays. Such collation of data is of paramount importance. It could serve as the basis for future policy reform or governmental schemes for CwDs. This data can also be used by organisations to better tailor their interventions to address the needs of CwDs. This data needs to be available along multiple identity axes including but not limited to age, gender, disability category, geographic location, socio-economic background, and so on.

Apart from such collation of data, there should be an increased focus on prevention of disabilities through awareness generation. A crucial avenue for this awareness is through maximising the utilisation of various government initiatives. Additionally, there should be streamlined efforts to build awareness of early intervention in the first 1000 days of childhood. This will ensure better prevention and identification of disability among children.

In order to identify and spread such crucial awareness on early intervention, Sarthak has been involved with conducting awareness sessions for various stakeholders over the years. The organisation has worked with Anganwadi and ASHA workers, parents and the larger community as well as engaged with CME interventions.

There are plans underway to strengthen such initiatives in the coming years as well, rooted in the belief that collaboration and multistakeholder interventions are key to providing timely support to CwDs. This need for timely support also informs Sarthak's commitment to digital solutions. The organisation hopes to improve the outreach and usage of the CapSarathi app as well as the forthcoming E-LMS system, GyanSarathi, to strengthen early intervention efforts. Through the IDEA initiative, the organisation also hopes to build the capacity of other organisations to adopt such multipronged engagement models involving different stakeholders.

The future of effective early intervention strategies lies in reaching out to more numbers of CwDs in need with robust, personalised solutions. The focus on data-driven decisions, online strategies and collaborations reflects Sarthak's commitment to this future.

11. ACKNOWLEDGEMENTS

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12. ANNEXURES

12.1 ANNEXURE A: BENEFICIARIES OF SARTHAK'S EARLY INTERVENTION SERVICES

DELHI

SR.NO	YEAR	DELHI CENTER	DELHI HIGH RISK CLINIC
1	2014-15	150	-
2	2015-16	218	40
3	2016-17	100	-
4	2017-18	105	19
5	2018-19	150	35
6	2019-20	206	26
7	2020-21	342	58
8	2021-22	361	-
	TOTAL	**1632**	**178**

GHAZIABAD

SR.NO	YEAR	GHAZIABAD CENTER	GHAZIABAD HIGH RISK CLINIC
1	2019-20	157	96
2	2020-21	206	21
3	2021-22	380	-
	TOTAL	**743**	**117**

12.2 ANNEXURE B: REQUIRED RESOURCES & PROPS FOR SARTHAK ANTAKSHEP KENDRA

OCCUPATIONAL THERAPY	REQUIRED RESOURCES	UTILITY/ USAGE
(Carpet covered flooring, so as to avoid any accidental hurting owing to falls/ slips)	Balance Beam	Balance & Coordination/Vestibular Input
	Balancing Board	For Balance Correction
	Balls - Therapy	To reduce hyperactivity/to give pressure improve body awareness
	Ball Pool	To work on Proprioception/Tactile issues/ Deep Pressure
	Bean Bag	Fine and gross motor skills improvement/ attention and focus/eye hand coordination
	Bolsters	Rolling/positioning
	Bubbles	To make child active
	Blocks	To improve attention and focus/gross and fine motor skills.
	Bouncing Balls	To improve body awareness and reduce insecurity
	Crash Pad	To avoid any kind of injuries/harm during exercise
	Crawler	Strengthening/ Crawling/ Motor-Planning/ Mobility
	Gaiter	To improve walking pattern/balance/position of feet
	Handcuffs	To exert extra weight on hands, so that child put more efforts to do task
	Hand Exerciser	To improve grip & reduce tightness
	Mats (Plain & Textured)	To provide different textures and touch
	Mirror Lights	To improve attention
	Parallel Bars	To correct walking or initiate walking with assistance
	Pillows	Positioning

OCCUPATIONAL THERAPY	REQUIRED RESOURCES	UTILITY/ USAGE
Carpet covered flooring, so as to avoid any accidental hurting owing to falls/ slips)	Prone Stander	Weight Bearing
	Rattle	To get child's attention for activities
	Scooter Board	Balancing/ Vestibular Input
	Soft Toys	To enhance touch
	Splint/ Braces	Support & correction of body joints
	Spoons	To improve gripping and teaching ADLs
	Static Cycle	For paddling and exerting leg pressure
	Supine Stander	Weight Bearing
	Swings	To work on vestibular/insecurities/sensory issues
	Textured Clothes	To work on touch
	Trampoline	Jumping and body balancing
	Treadmill	Physical strength exercises through walking and running
	Tumble Roller	Stimulation/ Vestibular Input/ Co-ordination/ Motor Planning/ Balancing
	Wedges	To assist positioning
	Wobbling Board	(Circular Motion) Balance

SPEECH THERAPY	REQUIRED RESOURCES	UTILITY/ USAGE
	Animal Sound Box	To teach different animal sounds
	Audio System	Sound orientation
	Bell	For sound orientation
	Books	For identification and concept building
	Bubbles	To work on air control and pressure while blowing
	Candle	To work on air control and pressure while blowing
	Chew Tubes	Chewing to improve oro motor muscles
	Drum	For auditory training
	Flash Cards	To assist concept building
	Ice Cream Sticks	To assist tongue movements
	Masks	Imitation

SPEECH THERAPY	REQUIRED RESOURCES	UTILITY/ USAGE
	Matchstick	To light candle for blowing exercise
	Mirror	For imitation
	Music Box	Sound orientation
	Stacking Rings	To build attention and focus
	Straws	To assist and improve sucking
	Tape Recorder	Sound orientation
	Toys (Fruits/ Animals)	To make child participate in sessions
	Vibrator Brush	To provide oro motor massage
	Whistle	To work on air control and pressure while whistling
	Xylophone	To improve attention and focus

SPECIAL EDUCATION ROOM	REQUIRED RESOURCES	UTILITY/ USAGE
	Blackboard	To write/make child write
	Colour Box	To draw outlines so that child write in the block
	Computers	To teach basic computer skills
	Flash Cards	To assist concept building
	Stationery	Pen, pencil, eraser, scale, sharpener, etc. for class use
	Sticker	To reward the child's success
	Story Books	To teach moral lessons and adaptive skills

OFFICE AREA	REQUIRED RESOURCES	UTILITY/ USAGE
	Books/ Newspaper Rack	To furnish latest and relevant information on display for visitors and team
	Cameras	To record movement and activities at centre
	Computer	To maintain a repository of data
	Cupboards	To keep things in place
	Display Board	To put a display of updates and plans of centre
	Height Scale chart	To observe child growth

OFFICE AREA	REQUIRED RESOURCES	UTILITY/ USAGE
	Knee Hammer	To check child reflexes
	Measuring Tape	To measure child's head circumference
	Reception Desk	To disseminate information to visitors
	Stethoscope	For physical examination of child
	Torch	To check eye movements
	Weighing Machine	To weigh child at the time of admission/at regular intervals
	Visitors' Chairs	To provide sitting space to visitors/parents
	First Aid Box	To maintain regular medicines
	Biometric Machine	Regular attendance of staff
	Telephone	Communication
	Water Dispenser	To provide potable water

STIMULATION ROOM	REQUIRED RESOURCES	UTILITY/ USAGE
	Ball Pool	Sensory Issues
	Disco Lights	To get child's attention
	Hammock	Positioning/Relaxation
	Hanging Toys	To get child's attention
	Hydro Pool	Sensory/Increasing flexibility/Relaxation
	Mirror	Imitation
	Moving Toys	To get child's attention
	Music System	Sound (Play soft songs/rhymes/mantra)
	Noise Making Toys	To get child's attention
	Sand Pool	Sensory Issues/Play
	Tractor Inner Tubes	Sensory Integration
	Wind Chimes	Soothing sounds to make child feel relaxed

12.3 ANNEXURE C: Gyansarathi ELMS for People with Disability

Sarthak Educational Trust is providing Services to People with disability across the life cycle.

i. **Early Intervention services for Children with Special Needs (CwSN)** – Occupational Therapy, Speech Therapy, Special Education, Behavioral Modification services for children with special needs based on their disability &/or developmental delays.

ii. **Inclusive Education services for School going Children with Special Needs** – Consultancy & Guidance to Government/ Private Schools & Assisting children to adjust to regular schools by remedial classes.

iii. **Vocational Skill Building for Youth with Disability** – Training support to youth with disability so as to prepare them for Employment Opportunities in Corporate, Self-Employment initiatives, Digital Literacy & Inclusion

iv. **Sustainable Employment of Youth with Disability** – Approaching & Engaging Corporate to hire PwD workforce and provide them equal opportunity environment as well as providing skilled PwD workforce to corporate.

v. **Advocacy to create Inclusive Environment for PwDs** – Engagement & Awareness generation to Government, Corporate, Media, Academia, PwDs & other stakeholders to contribute their share to bridge the existing gap and take initiatives to provide equal opportunity & Inclusive Environment to PwDs

vi. **Abilympics – Skill Based Competitions for PwDs** – Organizing regional, national events and representing India in International abilympics events.

All the above services are provided in Physical as well as Virtual set-up. To provide these services in a better virtual environment, Sarthak team is engaged in getting a dedicated Learning Management System for PwDs.

Sarthak Early Intervention Model

Early Intervention centers outreach Children with special needs through various mediums and counsel their parents to enroll child in regular therapy sessions & tell them its importance.

Once the parent gets the child enrolled in therapy sessions, detailed diagnosis and assessment is done, to assess or confirm disability and its degree. Accordingly Individualized Intervention Plan (IIP) is prepared listing the target areas of improvement and its timeline. This IIP is drafted by the OT, ST, SE and Psychologist in mutual consensus.

Once the IIP is made, therapies are started and children are monitored on regular frequencies to tap their improvements in the target areas and based on the developments progress is reported.

The records and data for all these steps such as outreach of Parents, Enrolment, Assessment & Diagnosis, IIP, regular progress review is updated on Sarthak's centralized MIS system.

Along with the services to CwSN, Sarthak also counsels and guides their parents so as to answer their queries, concerns and enable them to conduct these activities at their homes as well for better outcomes.

EI Services & GyanSarathi

Considering the idea of providing EI services in a virtual environment, Sarthak has updated its material and processes to make it more user friendly in an online environment.

Dedicated activities and their level wise videos and exercises are compiled and vetted by subject experts.

The complete process of EI services through GyanSarathi can be understood in a stepwise process –

1. Registration of Child at GyanSarathi by Parents by filling a Basic Information Form.
2. Sarthak Team will coordinate with the Parent and capture detailed information so as to Enrol the child for therapies.
3. After Enrolment, assessment and Diagnosis would be completed in 7 working days.
4. Based on the assessment outcomes IIP would be prepared and activities would be auto-suggested to the parents
5. Parents can then access their accounts refer to the material and conduct activities. Therapists will also connect with Parents on regular basis so as to guide them with appropriate information and map child's progress.

6. The activities are designed in a level wise manner with increasing difficulty levels and only appropriate levels considering the disability and its degree (Mild/Moderate/Severe/Profound) would be made open for the child.
7. Once the child clears one set of activity and achieves targeted level of improvement, next activity will get automatically assigned to the parents and therapist will get an update to guide the parent to do the same properly.
8. The complete progress with reference to IIP will be recorded in the system and the EI team can analyze the progress of any individual at any point of time.