

2.33 Samarpan: Early identification and intervention to check disability in Madhya Pradesh

Samarpan, in Madhya Pradesh, is a unique intervention conceptualised for the early identification, screening, treatment and rehabilitation of children with developmental delay or physical disability. Led by the Hoshangabad district administration, Samarpan's Early Intervention Clinic (EIC) realises a convergence model of the Departments of Public Health & Family Welfare (PHFW), Women and Child Development (WCD), and the District Disabled Rehabilitation Centre (DDRC). Every month, 1,500 children are examined in a coordinated exercise involving a vast number of health officials and converging existing schemes such as the National Rural Health Mission (NRHM) and the Mukhya Mantri Bal Hriday Upchaar Yojna. The relevance of this initiative was established in February 2013, when the NRHM launched the Rashtriya Bal Swasthya Karyakram, modelled on Samarpan. A total of 1,05,550 children were screened by Anaganwadi Workers using the 'Samarpan' screening test, and 2,311 children were identified with delays-in-developmental milestones as of March, 2014.

Rationale

The issue of comprehensive child health was brought into sharp focus through the NRHM. Apart from highlighting the need to arrest the glaring Infant Mortality Rate (IMR) in the country, such a focus also raised issues such as malnutrition, stunting etc. for policy and programmatic intervention. However, till February 2012, the NRHM did not address the issues of birth defects.

Globally, birth defects occur in six to seven out of every 100 babies born annually. In the Indian context, birth defects account for 9.6% of all new born deaths. There is a clearly visible policy gap in addressing issues of disability among children in India. Samarpan emphasises the criticality of employing twin concepts in guiding any policy initiative in this direction: one, the critical period of development of a child, and two, the role of specialist disciplines like neuroplasticity, which refers to the changes

in neural pathways and synapses which determine brain development.

According to critical period of development, the earliest signs of delayed development are identified in an under-5 child (U-5). The U-5 mark is critical, as within this span, specialised intervention offers a possibility of bringing the child almost to the normal curve of development. According to neuro-biological research, early experiences and stimulation are critical for optimal brain development of a child, suggesting that early intervention has the most critical impact.

These twin concepts guided the search for a plan of action to put these ideas proactively on the health map of the Hoshangabad district. The result was the launch of the Samarpan initiative, focussing on early identification and intervention in U-5 children in the district. This initiative and the impact that it has generated have also helped in addressing the policy gap at the national level by placing disability and early intervention on the agenda of the National Health Policy through the Rogi Bal Swasthya Karyakram (RBSK).



Image 1: Samarpan's Early Intervention Clinic (EIC), Hoshangabad district Madhya Pradesh

Objectives

The main objective of the initiative was to identify early signs of development delays in U-5 children in Hoshangabad district en masse, by conducting screening tests based on development milestones for the newborn and U-5 children.

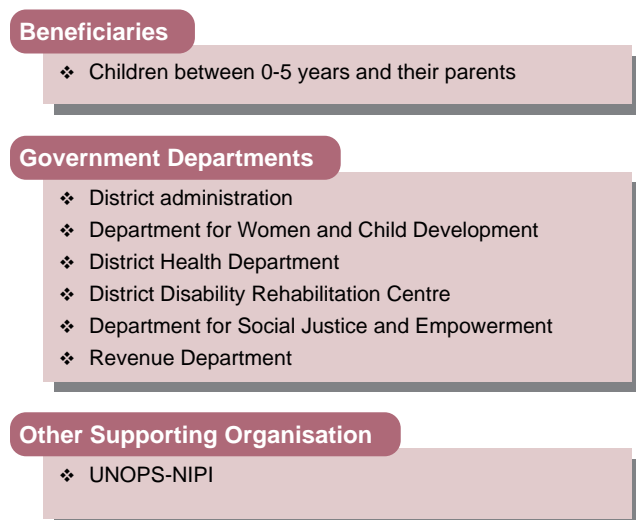
The initiative also aims to have a comprehensive facility under a single roof for the specialised and multi-disciplinary evaluation of children's social development,

visual development, speech and hearing development, mental development, and growth. It also endeavours to provide comprehensive and specialised intervention to remove or reduce development impediments at the Samarpan EIC. The initiative also strives to make society aware of the potential development issues children could face, in a bid to involve people in society-based and home-based identification. Another related objective of the initiative is to facilitate acceptance in the family about the onset of development delay in the infant, so that appropriate interventions may be sought and/or accepted.

Key Stakeholders

The nodal implementing agency was the district administration of Hoshangabad District, in convergence with various departments in the district such as Department for Women and Child Development (WCD), District Health Department, District Disability Rehabilitation Centre (DDRC), Department for Social Justice & Empowerment, and Revenue Department. The prime beneficiaries of this initiative were children between the ages of 0-5 years, their parents and their families. This initiative was supported by the United Nations Office for Project Services (UNOPS)-Norway India Partnership Initiative (NIPI).

Figure 1: Key stakeholders



Implementation Strategy

In August 2010, a national seminar on early identification and intervention was organised with representatives of national institutes working in the field of disability, with the purpose of ideating for the development of a blue print for effective intervention. Premier institutes such as the National Institute of Mental Health and Neurosciences (NIMHANS),

the National Institute of Mentally Handicapped (NIMH), the National Institute of Orthopaedically Handicapped (NIOH), the National Institute of Visual Handicapped (NIVH) and Composite Regional Centre for Persons with Disability (CRC) participated in the workshop. The workshop helped develop a sound perspective for the initiative and helped secure commitments in action from partners. For example, the Institute of Postgraduate Medical Education & Research (IPGMER), Kolkata, provided technical support and guidance in designing facility-based protocols, and later trained specialists of the Samarpan facility at IPGMER itself. Likewise, Secunderabad-based NIMH shared their screening test for community level application- Reaching and Programming for Identification of Disabilities (RAPID).

A district level convergence model for facilitating implementation was worked out over a series of meetings. The groundwork before implementation involved various activities including: contextualising RAPID to local needs to create the Samarpan Screening Test; preparation of training material and literature for sensitisation of local surveyors such as Anganwadi Workers (AWWs) and Accredited Social Health Activists (ASHAs); sensitisation of local surveyors to disability and the importance of early identification and training for conducting door-to-door surveys.

Following this, in September 2011, AWWs and ASHAs conducted door-to-door survey for identifying children with development delays. Apart from the above mentioned activities, the survey data was fed into a software called Vatsalya, which was developed through the resources of the WCD Department in 2009-10. The Vatsalya software enables collation of a monthly measurement history of each and every child of the district and calculates Age-To-Weight, Wasting, Stunting and Mid-Upper Arm Circumference (MUAC) grading automatically. This data is very useful for any clinical examination and available at a mouse click. This is an example of leveraging the resources (Vatsalya) from one



Image 2: Training of AWWs and ASHAs in Hoshangabad

Source: Samarpan, Hoshangabad

department of the government (in this case, the WCD Department) for the benefit of the Samarpan initiative. Among other steps, the Vatsalya software was linked to the Samarpan software, which was specially designed in order to store case specifics such as parental history, detailed birth history of the baby, developmental assessment, assessment of hearing and visual functions, intervention strategy and periodic evaluation, to aid identification of children in the entire district showing signs of delayed development.

Also, the convergence between various departments helped in setting up a facility for intervention at the DDRC. The reluctance of families towards bringing their children to the DDRC and resistance within families to accept possible disability in their child led to renaming DDRC with a more positive sounding name Samarpan, which, in Hindi, means dedication, thereby implying dedication of DDRC to the cause of early identification and intervention in cases of disability.

The Samarpan facility was set up to provide a comprehensive range of services including medical services for preventive health and immunisation to women, along with child services for ensuring proper nutrition and development of children. The facility also provided services such as neurological assessment, physiotherapy, occupational therapy, psychological services, and cognitive development support for socialisation, vision, speech, language and hearing. The Samarpan facility needed equipment, infrastructure and manpower enhancement to meet the needs of its new role. Institutions such as UNOPS-NIPI, the Red Cross Society, Rotary International, and the State Bank of India supported various components of the intervention facility. Further, the available resources of various district level departments were converged to set up this facility.

a. Innovation

The critical innovation of Samarpan was to bring the twin concepts of critical development period and neuroplasticity on the policy agenda for the first time. It devised a comprehensive multi-disciplinary approach to intervention. The structure of the intervention was also aimed to capture any allied disability that might develop as a result of the prominent disability.

b. Training

Since the initiative needed identification of development delays in U-5 children en masse, it was critical to conduct a preliminary survey to identify potential cases for detailed investigation at the facility. The services of the AWWs

and ASHAs were harnessed for this purpose. Through ASHAs the new-borns and premature children could be identified and tracked, while AWWs had presence down to the sub-village or hamlet level and were in daily contact with children U-5. Trainings were conducted for the initial survey, contextualised from RAPID to suit the local needs. After development of the Samarpan survey, training booklets in Hindi were prepared to train the surveyors in conducting the Samarpan Test. To accommodate all the AWWs and ASHAs, cinema halls were hired for conducting the trainings. In all, 25 trainings were conducted for this purpose.

Apart from this, Samarpan specialists underwent advanced trainings at IPGMER, Kolkata. Consequently, the physiotherapist, child psychologist and special educator, audiologist, speech and language pathologist, nurses and auxiliary nurses and midwives were also trained at IGPMER in 2011.

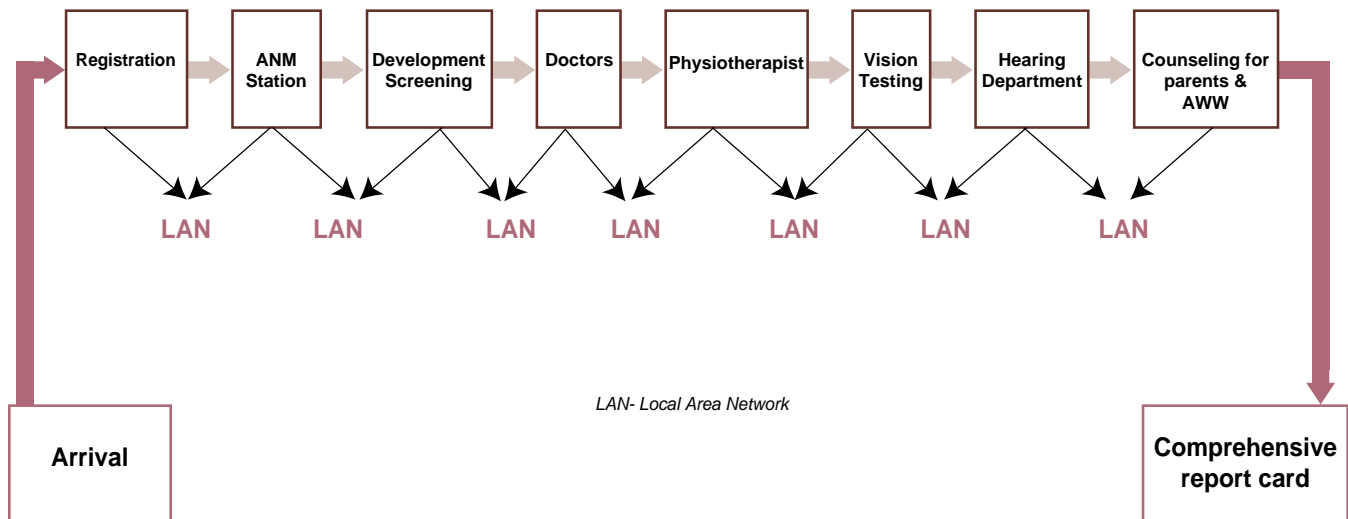
c. Awareness generation

Since this was a first of its kind initiative, a lot of stress was placed on awareness generation through Information, Education and Communication (IEC) activities. The project engaged with artists from the Social Welfare Department to generate awareness through *nukkad nataks* (street plays) on the issues of disability. Wall paintings related to disability were placed at strategic locations. Traditional means of *duggi pitna* (announcements) in villages were undertaken to sensitise the community on the issues of disability. Pamphlets and advertisements were also used to spread consciousness. Panchayat secretaries, ASHAs and AWWs were trained and encouraged to spread consciousness through word of mouth due to their strategically advantageous position in the community.

d. Process flow

After the survey was conducted, the data was uploaded on the Vatsalya software and potential cases of development delay were identified. The next step was to bring these identified cases to the Samarpan facility to conduct diagnosis by specialists and suggest intervention. In order to enable the children and their parents to visit the Samarpan facility, transportation for children and their parents was also arranged.

Each day, a route chart for the ambulance was prepared according to the capacity of the Samarpan facility to screen children for investigation in the course of a working day, and accordingly, AWWs were informed. The AWWs communicated the same to the parents and accompanied the child and parents to the facility.

Figure 2: Process flow of screening U-5 children in Samarpan centre

Source: Samarpan, Hoshangabad

The process at the facility started with the registration of the child, followed by a detailed screening for any signs of development delay. Figure 2 provides details of the process flow at the facility.

The initiative developed a comprehensive multi-disciplinary approach to interventions bringing various specialists under one roof. The identified children were then recommended for specialised intervention with training given to their care-givers, as well as mothers and AWWs as required, for ensuring that home-based interventions are also provided.

e. Monitoring

The initiative had an inbuilt mechanism of monitoring as the entire process was digitised. The details of the survey were fed into the Samarpan software and the experts reassessed development delays in all the children surveyed. Identified potential cases were registered at the facility with corresponding details entered in the software system. The software ensured smooth monitoring as the details of the facility's functioning and cases were a mouse-click away. Further, the Samarpan website, www.samarpanhoshangabad.org provided all relevant information to the public.

Resources Utilised

The initiative was an innovative effort on part of the district administration. No clear budget was assigned for the implementation of Samarpan, and it depended

heavily on the convergence of available funds from various departments such as the WCD Department, the District Health Department, the DDRC, and the Social Justice Department. Some private entities also assisted in small measures. The Red Cross Society financed the development of the Samarpan software. The State Bank of India donated a bus from their corporate social responsibility fund to the Samarpan facility for picking up and dropping children. Similarly, UNOPS-NIPI financially assisted in developing the Samarpan facility at DDRC at Hoshangabad.

The estimated cost for upgrading the DDRC to a Samarpan facility was Rs. 21 lakh approximately. This facility required experts in various disciplines. Human resources from various departments were pooled in to this end, in order to ensure smooth running of the facility as conceived. Previously the DDRC had one physiotherapist, one psychiatrist, one child psychologist, a special educator, an audiologist, a speech and language pathologist, occupational therapist, and an optometrist. To add to this, the district hospital provided one pediatrician from the Sick Newborn Care Unit (SNCU, District Hospital), an Ear-Nose-Throat (ENT) specialist, an ophthalmologist, two nurses and three ANMs. Further, other doctors from the district hospital contributed to the Samarpan facility when required.

Impact

Coverage of U-5 children and provision of treatment: The initiative aimed to cover all U-5 children in the district in the initial phase, which was a huge task given the difficult terrain of the district.



Image 3: Three-year old Vikki with his mother after his cleft lip surgery in March 2014 in Hoshangabad

Source: Samarpan, Hoshangabad

As of March 2014, a total of 1,05,550 children were screened by AWWs using the Samarpan screening test in Hoshangabad. The process helped identify 2,311 children with delay in attaining development milestones. Under this programme, 941 children were examined in the Samarpan facility out of which 599 children were identified as requiring intervention by the specialists. Sometimes, while undertaking interventions to address identified developmental delays in particular cases, other types of disabilities were also observed in the individual and suitably dealt with.

A follow up through special education at block level was done for 606 cases of mental retardation by March 2014, which found that 50-60 of such children have responded well to the intervention and are showing signs of up to 70% recovery. 572 physiotherapy cases were also identified and followed by suitable interventions. Apart from this, as of March 2014 audiology counselling was made available to 113 cases and around 312 cases with the requirement of speech therapy were also assisted.

By the same date, suitable interventions were provided in 145 cases related to vision services, 48 cases related to hearing aid, 14 cases related to Congenital Talipes Equinovarus (CTEV) surgery (for club-foot), 61 cases related to shoe arch, four cases related to Coronary Heart Disease (CHD) surgery, and 10 cases related to Portable Powered Ankle-Foot Orthosis (PPAFO) surgery. In two cases, callipers were distributed while modified shoes

were provided in five other cases. In six cases, gaiters were also made available through this initiative.

Data as of March 2014 also shows that the initiative provided self-help skill training in 570 cases and parents' counselling in 941 cases.

Increased acceptance of disability and treatment-seeking behaviour: The social impact of the initiative was significant, especially as it led to an increased acceptance of disability in society, and encouraged people to seek required treatment. Samarpan made positive efforts to mainstream people with disability. A small child with mental retardation was invited to inaugurate the Samarpan facility with the aim to ease the stigma attached to disability.

Societal sensitivity to persons with disabilities and mainstreaming: Consistent IEC activities ensured that society was encouraged to be more sensitive to disability. Apart from therapeutic and specialised interventions, the Samarpan team also provided assistance and support to enroll these children in schools. This worked positively in mainstreaming them in society.

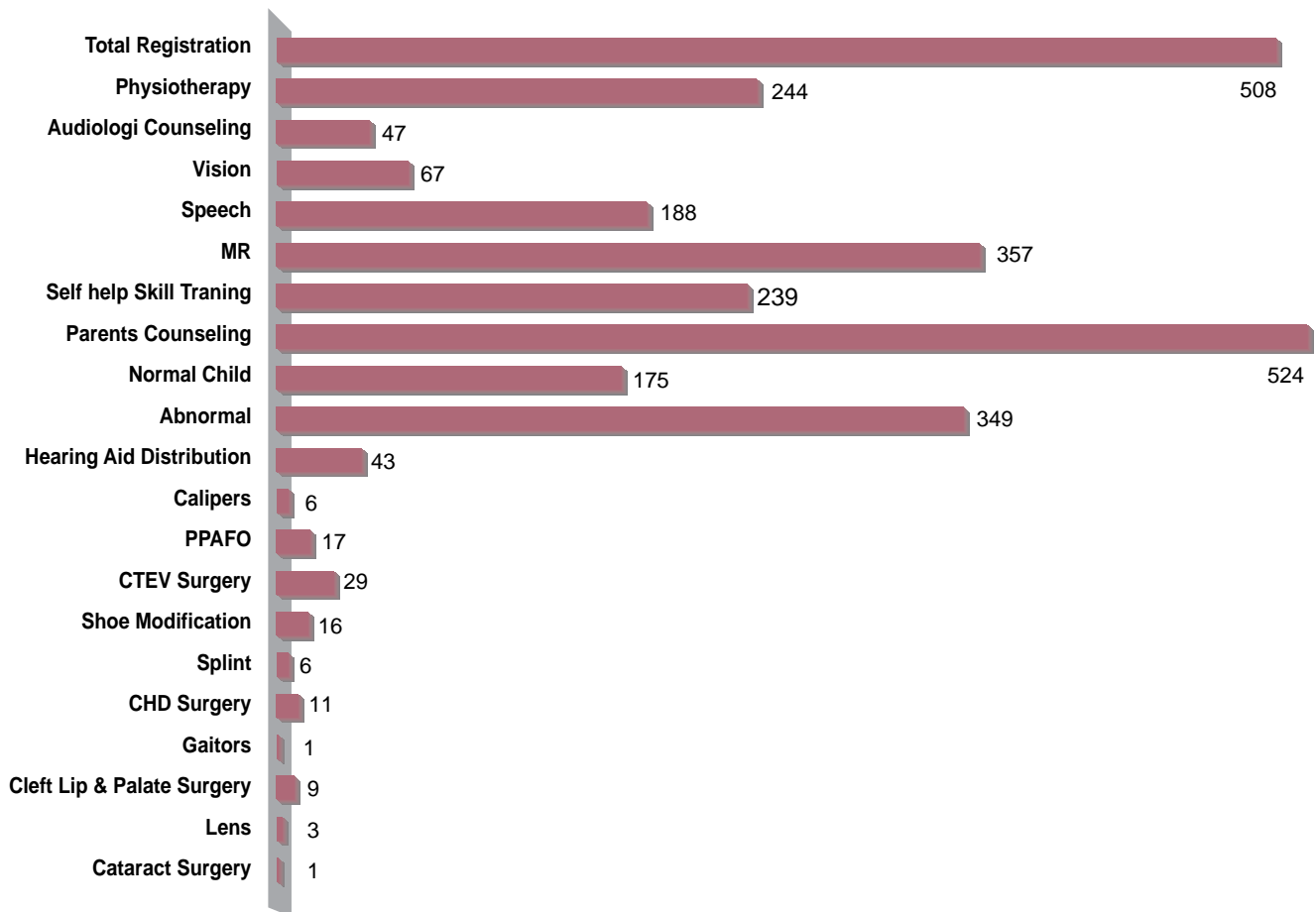
Key Challenges

A total lack of any policy direction to guide the practical roll-out of the initiative was a big challenge. There was no policy in India that took a preventive perspective on disability, especially in the case of children. Hence, the initiative took a long time and research to take shape.

Another big challenge was the lack of adequate awareness and sensitivity about the issues of child disability such as critical development period, and neuroplasticity among the local doctors and other health workers. Lack of funds available with departments to contribute towards implementing the Samarpan initiative was also a stumbling block.



Image 4: Five-year old Muskaan Patel had heart surgery in November 2012 in Hoshangabad

Figure 3: Kinds of interventions undertaken by Samarpan Facility

Source: Samarpan, Hoshangabad

Resistance among parents to accept disability in their children is also an impediment along with social resistance towards accepting disability. Also, resistance to bring identified children for periodic follow-ups by parents from economically weaker sections also poses some challenges. There was also a lack of tertiary link-ups, i.e. the DDRC had no linkages with larger medical centres providing a wider range of specialised services, and this limited its ability to treat cases requiring extremely specialised interventions.

Replicability and Sustainability

The initiative was highly successful and the District Collector spearheading it was invited to be an adviser to the national level programme (i.e. RBSK) that aimed to fill the policy gap related to disability in children. With the launch of the RBSK at a country-wide level under the NRHM in February 2013 for early detection of health conditions in children, the Samarpan initiative has effectively been scaled up to cover the entire country.

The experience and learnings from the initiative critical to the successful implementation the RBSK in India. The Samarpan facility in Hoshangabad, Madhya Pradesh, serves as a model for the RBSK. This is demonstrated by the fact that other states have visited the Samarpan facility in Hoshangabad to learn from their experiences.

Conclusion

With the launch of the RBSK, many new additions have been introduced in Samarpan. The Samarpan DDRC facility continues to function with additional features – there is now a district RBSK coordinator to ensure smooth convergence between DDRC and District Hospital and also address any grievances that might arise. In order to improve accessibility to the Samarpan facility, the concept of Mini Samarpan is being implemented in Hoshangabad district on an experimental basis. This involves the establishment of one small Samarpan facility called Mini Samarpan for every two blocks. The Teaching Learning Material kit is also being distributed to various needy

children after the launch of RBSK. Further, a hostel is being constructed for severely disabled children on the premises of the Samarpan facility in Hoshangabad. The idea is to provide intensive training to the child and care-giver for 10 days at the Samarpan centre, following which the children will be monitored by the specialists stationed at the Mini-Samarpan. This intensive training will be followed up with a further 10-day refresher training for the children and their care givers after six months.

The initiative has achieved more than it had expected by facilitating the evolution of a new policy addressing

the existing gaps in children's health and disability. Even though the implementation of the policy is at a nascent stage, Samarpan Plus has been initiated after the launch of RBSK in Bhopal District as another initiative to take care of policy gaps that still exist. Samarpan Plus aims to learn from the challenges faced in the Hoshangabad pilot, especially providing the tertiary links in cases requiring surgery. Samarpan Plus differs from RBSK as it caters to the largely urban population that does not fall in the ambit of the new policy that caters only to the rural population. Thus, this initiative continues to direct policy intervention wherever there is a policy gap.

Fact Sheet

Theme	Social Security
Nodal Implementing Agency	District administration of Hoshangabad District
Geographical Coverage	Hoshangabad district of Madhya Pradesh State
Target Groups	Children in the age group of 0-5 years
Years of Implementation	2011 - Present