

# SAMARPAN

## Early Identification and Intervention to check Disability

### PART - I

The public toilet stank of excreta and urine. With an unmistakable stench of tobacco in air, the dirty premise was a typical *sarkari* public toilet. In its present state, it could have only been used by a brave heart under severe compulsion of a call from nature. Wankhede was distraught at the sight of it but the call of nature had to be answered. He took a deep breath and went inside. What he saw next had a profound impact on him.

A girl child, no more than 3 to 4 years of age was struggling unsuccessfully to use the toilet. A closer look at her made him realize that the girl had some sort of physical disability, because of which she wasn't able to squat. Being collector of the district, he felt ashamed of the fact that the toilet was practically un-usable and little had been done by administration to mitigate simple sufferings of disabled like the one he had just witnessed. While he helped the girl, he was now acutely aware of the fact that this one instance would really not amount to much help in the larger scheme of things. He resolved to do something concrete and lasting about the welfare of the disabled, particularly for young children in his district.

He was surprised to learn the fractured way in which Government dealt with the issue of disability. Department of social justice was dealing with welfare of the differently abled. The District Disability Rehabilitation Centre<sup>1</sup> (DDRC) and other welfare measures undertaken by the Government came under it. The WHO definition of health however included mental well being of individual also and indeed, without active linkages of health personnel, little treatment and rehabilitation can be done. Further, department of women & child development (WCD) was involved as referral services are one of the core services under the Integrated Children Development Services<sup>2</sup> (ICDS) mission. Apart from these directly involved departments, there were many more departments and institutions such as public relations, school education, panchayat etc. which had something or the other in common with welfare of the disabled. Yet, the common thread of integration was conspicuously absent.

He knew that it is a fact that awareness about disability is abysmally low even among district level officials and the measures taken by Govt. to mitigate it is inadequate. Govt. departments generally operate in silos and cooperation amongst them, particularly at grass root level, has always been a challenge for administrators. In other words, a person seeking services for intervention and rehabilitation of disability would have to find ways to avail Govt. services, running from pillar to post, that too if in the first place such services are available in a Govt. set up! For him, it was yet another classic example of a joint mandate, having fractured outcome.

The subject matter fascinated him and he decided to improve his understanding on welfare of the disabled. Having read psychology as an optional paper in main examination of civil service, he had a fair idea about mental disability. Further review of journals and literature revealed causes of disability to be attributable to a disease or

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<sup>1</sup> District Disability Rehabilitation Centre

<sup>2</sup> ICDS mission: launched in 1975 for early childhood development and nourishment supplementation by GOI

defect at the time of birth or an injury and also lack of an enabling environment. He also became aware of the critical role of the absence of essential micronutrients and malnourishment as contributing causes in infancy stage. He was astonished to learn that developmental impairment is a common problem in children health that occurs in approximately 10% of the childhood population and screening and early intervention of children directly contributes in improving the survival outcome of children. On the other hand, the adverse effect of failing in early identification and early intervention can lead to irreversible developmental damage.

While going through the literature, the concept of critical period of development<sup>3</sup> in human life cycle, neuroplasticity<sup>4</sup> and developmental milestones<sup>5</sup> caught his imagination. If these scientific concepts can be translated into practical reality through some mechanism, could it not result in reducing the incidence of disability? Further review of literature on neurobiological research clearly suggested that early experiences and stimulation are critical for optimal brain development, suggesting considerable capacity of early intervention to affect the child. He learned that brain is most malleable and formative during the first three years; by 3 years, a child's brain is about the size of adult brain. However, for a child to learn and develop properly, the extent and type of environmental stimulation the child receives in infancy and childhood is a decisive factor. He realized that along with medical problems and health issues, cognitive ability, motor ability, vision, hearing, speech and language, social communication abilities, functional limitations in essential activities have to be taken into consideration to understand disability in children. Study after study suggested that early detection and consequent early intervention for disability in a child gives her a better chance for adaptation, enabling mild to moderately affected children to have normal life and severely affected children to have improved outcome, thus decreasing the load of differentially abled people.

He thought it prudent to take stock of the current situation and identify the key problems. Putting himself in the shoes of a common man and relying on his own experience, he set out to identify all possible problems and related issues he could think of before launching an initiative on developmental delay and disabilities.

In addition to poor awareness about delays & disabilities at large, novelty of initiative as the topic of early identification and intervention for development delays or disability in U5 children, which was new for the district administration, was a challenge. A screening programme for early intervention of development of disabilities for children from birth to

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<sup>3</sup>Critical period of development refers to a specific time during which the environment has its greatest impact on an individual's development. It is the time during gestation when critical organ systems are formed. (Mosby's Medical Dictionary, 8th edition. © 2009, Elsevier)

In general, a critical period is a limited time, in which an event can occur, usually to result in some kind of transformation. In developmental psychology and developmental biology, a critical period is a phase in the life span during which an organism has heightened sensitivity to exogenous stimuli that are compulsory for the development of a particular skill. If the organism does not receive the appropriate stimulus during this "critical period", it may be difficult, ultimately less successful, or even impossible, to develop some functions later in life (Wikipedia online)

<sup>4</sup>Neuroplasticity refers to neural pertaining to the nerves and/or brain and plastic, moldable or changeable in structure, refers to changes in neural pathways and synapses which are due to changes in behavior, environment and neural processes, as well as changes resulting from bodily injury

<sup>5</sup>Development milestones refer skills gained by a developing child, which should be achieved by a given age. Examples include smiling by six weeks and sitting unsupported by eight months. Failure to achieve a particular milestone by a given age is indicative of developmental delay. (A Dictionary of Nursing, 2008)

5 years has never been tried earlier suo-moto by administration anywhere else in the country. Wankhede was worried as extensive search revealed that no practical model for early identification of symptoms of disability or delays in children existed and if attempted, it would be the first of its kind model in the country. Apart from his own little knowledge, he had practically no experience on early identification and intervention for development delays or disability.

Review revealed that there are very few centres in India which provide early intervention services but even most of these centres do not have all the components required for evaluation and intervention in a holistic way. The medical colleges have Eye, ENT, Psychology, Physical Medicine departments, but neither the instruments nor trained specialists are available to address the problems of the most critical period of child development i.e. the first three years of life. The paramedical staff like the optometrist, audiologist, clinical psychologist, physiotherapist staff are not trained to handle the U5 children in a comprehensive way, thus missing the critical period of development window.

In the Government set up, districts have DDRC under department of Social Justice & Empowerment (SJ&E), which caters to all aspects of disabilities and rehabilitation. However, Wankhede's district DDRC, like most other DDRCs in the state, was dysfunctional and poorly equipped as screening for identifying delays of development in U5 children was not thought of in the first place. In other words, DDRC's functioning as an early intervention centre was not envisaged.

Further, the first sign of any type of possible developmental delay or disability in U5 children was not being looked into at community level by the Govt., leading to late detection and loss of most critical period of child development. The poor level of awareness in society, coupled with the social stigma associated with disability and fractured functioning of Govt service providers made the case for early identification and intervention all the more challenging.

He reckoned that realization of a young one in a family being challenged comes as a shock to her near and dear ones. The social stigma associated with disability forces the family-the first and foremost to observe the early symptoms- to ignore them and indulge in wishful thinking of cure on its own, leading to late detection and loss of precious infant years thereby making the case difficult for intervention.

Wankhede had an additional challenge of weaving an interdepartmental, inter-sectoral and inter-institutional tailor made programme to achieve the objectives through convergence. This required, *inter alia*, division of workload, planning for resources mobilization, capacity building and regular monitoring, review and evaluation.

Prior to joining the IAS, Wankhede had worked as Child Development Project Officer<sup>6</sup> (CDPO) in WCD department in a remote block of the state and had a firsthand experience of realities of administration, particularly those of health and ICDS, at the cutting edge. Having worked in Govt. set up for the past 10 years, Wankhede had no illusions about the convergence (or the lack of it) between Govt. departments and knew from his own experience as one of the most difficult things to implement.

He thought it would be wonderful to have a centre, having trained human resources with all relevant machinery and equipment, wherein all types of early intervention services for U5 children can be rendered. Such an initiative could only be carried through convergence between various government departments as also society. Nonetheless, the more he thought of it, the more he found himself warming up to the idea and slowly a broad framework started to emerge. He decided to give the initiative his best shot and named it Samarpan.

Wankhede called for a meeting of all concerned departments who had a role to play in implementation of Samarpan. He ensured that decisions taken in the meeting are circulated in the form of minutes the same day, in addition to making it mandatory for all to be represented by the district level officers. As a result of prior planning, the meeting was well attended and Wankhede could sense bewilderment and anxiety amongst the district level officers.

He started the meeting with a power point presentation in which he explained the concepts of critical period and neuroplasticity in great detail but in simple language and with local relevant examples so as to make sure that each and everyone present in the meeting knew the importance of their contribution for the success of Samarpan. Wankhede wanted the initiative to be owned by contribution of all the concerned departments and he knew, in order to do so, the internal motivation of concerned official would play a key role. To underline the importance of Samarpan, Wankhede also announced in the meeting that a detailed meeting on Samarpan would be held every Monday immediately after the TL<sup>7</sup> meeting.

Though the DDRC of his district was located in the hospital campus and the infrastructure and human resources required for Samarpan could easily be made use of from the existing structure and staff of DDRC, it was clear that capacity building through dedicated training schedule for all concerned would have to be carried out to ensure that all U5 children are screened and the subsequential processes relating to it are clearly understood.

On close inspection, it was clear that the infrastructure of DDRC required a sea-change not only in terms of equipment but also in terms of having disabled-friendly toilets, wait areas and play areas where positive U5 children would be seated, awaiting their comprehensive check up. Based on the interactions with experts, which were going on for awhile now, human resources mobilization, particularly those which were technical in nature such as psychologist, audiometrist etc., also started in earnest. Discussions with experienced people in the field of early intervention had resulted in generation of exhaustive list of technical equipment which the centre essentially required were to be

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<sup>6</sup> CDPO:- The ICDS is implemented through a project, which roughly commensurate that of a block in a district. The CDPO is a manager of one such project, whose function is to manage the ICDS in his project through AWCs.

<sup>7</sup> Time Limit Meetings: Coordination amongst all line department is carried out by the office of Collector and it is a general practice in most districts to have a 'Time Limit' meeting on a given day every week in which important tasks are assigned a certain time limit in which they are supposed to be accomplished.

procured and more importantly, training for skilled technical persons to operate these *state of art* machines would have to be imparted and places and resource persons where this training could be carried out would have to be identified and tied up.

Wankhede noted that earliest identification of developmental delay is a must as waiting for cases to turn up may result in loss of critical period of an infant. This meant that some sort of screening would have to be done on *all* U5 children in the district *suo motu* in order to harness maximum critical period. This also meant that this *en masse* screening would have to be repeated preferably every quarter or at least twice in a year as different milestones of development had different period of onset in the development cycle of an infant.

Aware of the fact that the task of registering and providing services to all new born upto the age of 6 years is the core responsibility of ICDS, he thought that Anganwadi centres (AWCs) should ideally be the focal point of screening.

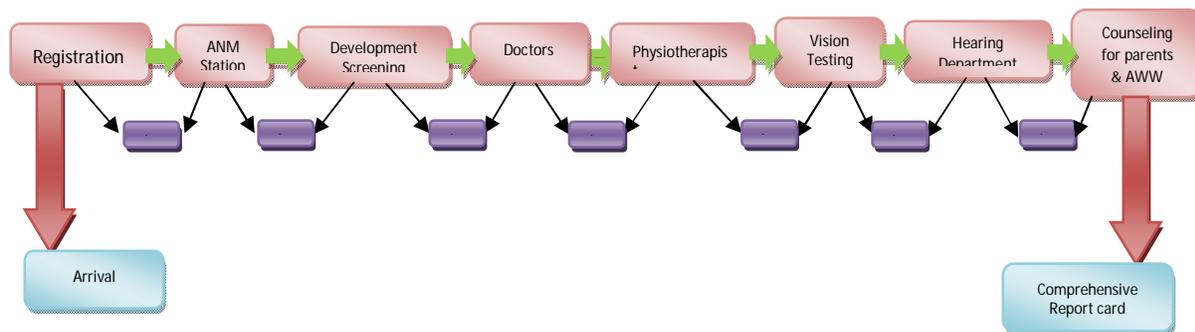
Further review of literature on internet about early intervention services by using search engines had revealed useful information on screening and intervention services, in particular, literature developed by National Institute for Mentally Handicapped, (NIMH), Hyderabad under their Reaching and Programming for Identification of Disabilities (RAPID) programme, which turned out to be a goldmine for further understanding the concept and roll out of Samarpan.

Capacity building of officials, particularly of Anganwadi Workers (AWWs), Accredited Social Health Activists (ASHAs), supervisor of health and department of Women & Child Development, block level officials and district level officials would have to be done in a concrete manner for which training modules have to be developed. Having discussed how best the capacity building can be done at all the levels in the meeting, a training schedule, based on the developed module in vernacular, was chalked out. Office of the Additional Collector, Development was made responsible for capacity building.

Constantly working on back-end process and goals, Wankhede thought that it would make sense to simultaneously utilize the time to generate awareness about delays and disabilities and also the importance of critical period and neuroplasticity in district level officials as well as the general populace of the district. Development of literature in vernacular for parents and AWWs, that also with emphasis on pictorial representation, keeping in mind the poor literacy in rural areas, was another activity which was done simultaneously, for which responsibility was given to a Senior Deputy Collector.

The suspected positive cases, screened at AWCs/residences, were supposed to be brought for their evaluation at the Samarpan, located in the district headquarter, because It was decided that a comprehensive check on a suspected positive case of U5 child would have to be carried out so as to not only confirm her/him as a true positive for delay of disability in that particular trait or field but also to find out whether the child has more than one type of delay or disability. This was done because review of literature on internet had highlighted that a child having one type of delay has greater chance to have delay in more than one trait. Wankhede, therefore, adopted the multi-disciplinary approach for the early intervention services proposed to be provided at the district head quarter. He thought it will be ideal for the child to enter the building at one end and get registered immediately upon entering the building. The child would then be subjected

to go to different rooms in the building just like the bogies of railway train so that all the required tests of different delays one after another could be carried out and a comprehensive report would be ready when the child exits the building.



This way, Wankhede thought that his Samarpan will provide the facility of early identification and intervention of development delays in which it would be easy to detect early signs of delays in U5 children in the district and also to have a comprehensive specialized multi-disciplinary evaluation of child for social development, visual development, speech and hearing development, mental development and normal development growth under a single roof. He also thought Samarpan would be able to provide comprehensive specialized multi-disciplinary intervention to remove or reduce developmental impediments and would further facilitate acceptance in the family about onset of development delay in the infant/U5 child, besides making the society aware about the concept of early intervention; increasing acceptability of disability in society and to involve it in society-based and home-based identification and intervention.

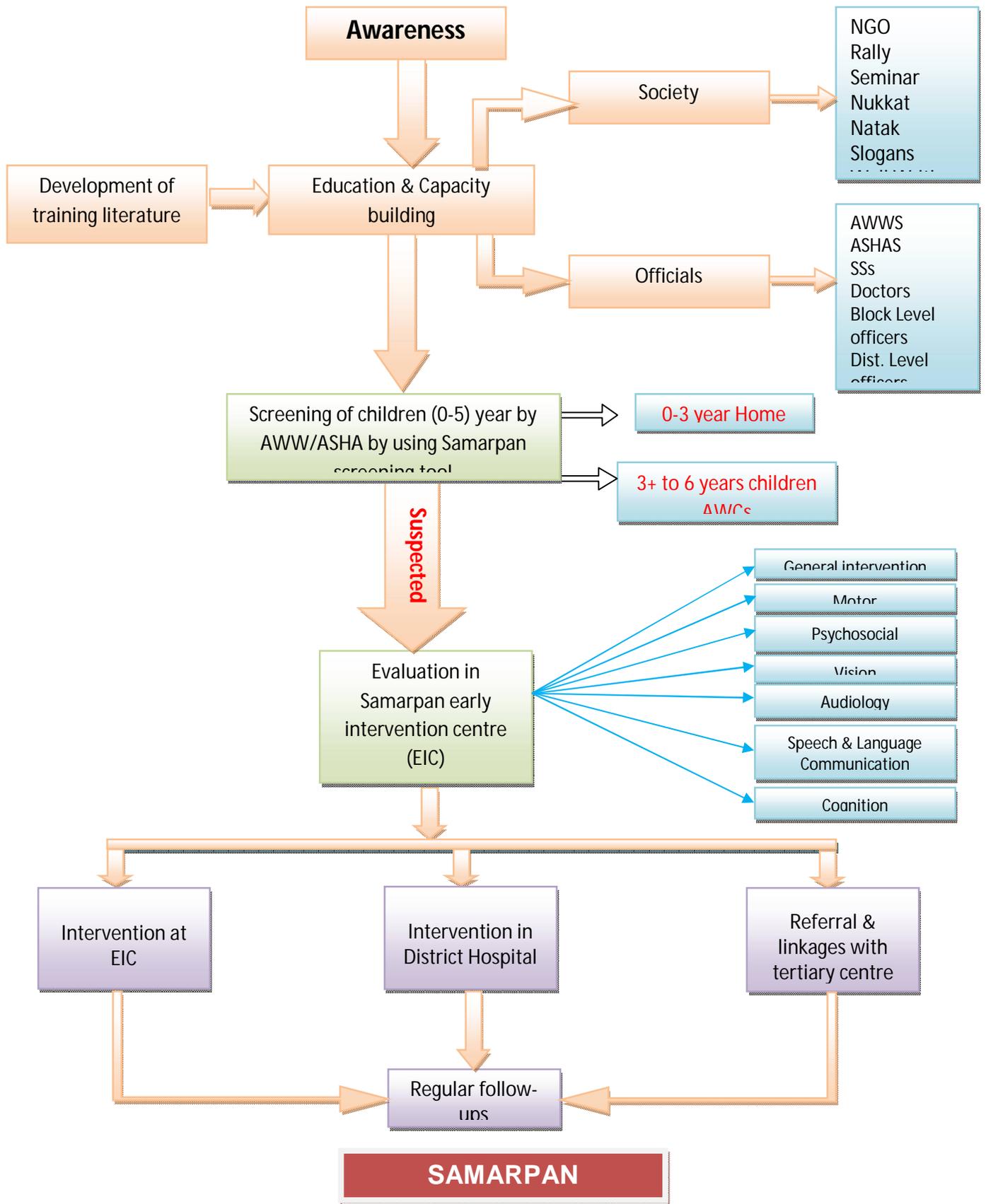
Like all administrators, Wankhede desired to have a rough idea as to what this initiative would cost in terms of financial, human and temporal resources. The initiative required one time investment (in infrastructure, machine, and equipments etc.) and provision for recurring expenditure (such as salary, recurring bills etc.). In terms of human resources, personnel of department(s) of WCD, Health & Family Welfare (H&FW), SJ&E and Revenue and other related departments, roughly numbering about 4000 would have to be involved in the initiative.

Simultaneously, he also gave a hard look at the budget allocations of different departments and schemes such as National Rural Health Mission (NRHM), SJ&E, ICDS, Panchayat & Rural Development (PRD), Sarva Shiksha Abhiyan (SSA) etc. While going through the financial allocation of line departments & availability of funds at different departments, it was clear that there exist sufficient funds which can be effectively utilized to roll out Samarpan, without actually asking the state government to allocate special funds for the initiative. For example, Nirashrit Nidhi<sup>8</sup> of the SJD allowed every district collector to use the interest amount of the Nidhi upto Rs. 2 lakhs. Similarly, by restructuring the flexi funds under NRHM, substantial amount of funds can be harnessed for rolling out Samarpan as diagnosis and treatment of disability is very much a part of health mission.

Having spent more than a year on back end awareness processes and capacity building, Wankhede's Samarpan was finally ready to be rolled out.

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<sup>8</sup> Nirashrit Nidhi is a fund, which is financed by way of 0.02 percent of total revenue, generated through auctions in government *mandies*.



## PART - II

Samarpan screening test<sup>9</sup> (SST) was given to AWWs and ASHAs of the district and they were asked to examine all U5 children registered in ICDS through this tool. Wankhede has personally taken the capacity building programme of AWWs and ASHAs in smaller groups at supervisor level because he knew the success of the initiative largely hinged on successful screening of all U5 children in the district. Successful screening could only be done by the grass root level workers of Anganwadi and ASHAs and as such, they were the bedrock of practical implementation of Samarpan. The AWWs and ASHAs were asked to go to the residences of under the age of 3 years (U3) children under ICDS as they were fed by their mothers in their residences by supplements of Take Home Ration (THR). The screening was carried out by AWW/ASHA workers for children between 3-5 years of age at the Anganwadi Centre. Throughout, it was emphasized that not a single child should be bereft of the screening.

In a short period of two weeks, as many as 1,50,000 U5 children in the entire district were thus screened either at the Anganwadi Centres or at their residences<sup>9</sup> by AWWs and ASHAs.

Screened children were then brought to the samarpan centre for evaluation and intervention in a holistic way. Comprehensive services ranging from Medical services (preventive health and immunization); Women and child services (nutrition and child feeding advise); Neurological assessment; Physiotherapy; Occupational Therapy; Psychological Services (DSCII & DDST); Cognitive Development (Play and Socialisation); Vision; Speech and language and Hearing were provided under a single roof.

His experiment with early intervention had passed the litmus test of practical execution. However, the euphoria and excitement of rolling out Samarpan turned out to be short-lived as practical problems of rolling out started emerging one after another. He had anticipated some of the bottlenecks which presented upon the execution but he was taken aback by the magnitude and variety of problems which the district administration now faced.

Screening more than 1.5 lakh U5 children in the district resulted in generation of huge data which the WCD found difficult to handle. To identify true and positive cases amongst this data required meticulous supervision by the supervisor level and officers, which was a taxing affair. Some AWWs were simply just not motivated enough to go to the residences of U3 children and examine them through SST. The profile of AWWs varied from one place to another making it difficult to have a tailor-made capacity building module uniformly across the district. Additionally, seasonal migration of poor folk, who often belong to the weak social strata in search of gainful employment, made it difficult for the concerned AWW to ensure that all children are screened. Though comprehensive screening under the multi disciplinary approach is ideal way of providing early intervention services but it would normally take about 2-3 hours for a single child to be comprehensively examined. As SST has been rolled out in all the blocks of the district, the number of suspected cases crossed more than 5,000. This made the task of screening each and every suspected case comprehensively under one roof at the district level challenging one indeed. To add to this woe was the issue of commuting from grass root level to district level for carrying out comprehensive tests.

Comprehensive testing also required consent of the parents. One of the major problems faced was that the parents, being poor, had to face loss of the daily wage, which

demotivated them to come to Samarpan in first place. Issue of providing food and beverages at the Samarpan also cropped up as apart from providing safe drinking water, provisions for food and beverages for suspected cases, their parents and concerned AWWs and ASHAs who were supposed to be all present was not just thought of.

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<sup>9</sup> The process of identification of earliest sign of developmental delay was done by applying a screening test, which was based on different developmental milestone of life cycle development. This test was named as SST.

In addition, several other issues cropped up when batches of suspected cases started pouring in Samarpan at district headquarter. Wankhede would make it a point to visit the centre almost on a daily basis and he was aghast to find that on certain days, the crowd would be far too high to handle and on other days would have very less suspected cases. The staff at Samarpan was quite new to the situation and lacked the ideal coordination among them for want of manager who would sort out the problems. Then, there was the issue as to who shall coordinate the documenting progress of multiple delays and disability while examining the child for want of a clear format.

Conditions prevailing at Samarpan made him realize that a robust framework for monitoring and follow up would be required if true positive U5 cases have to be given effective intervention. Initially Wankhede had thought of providing home based intervention by giving them literature and counseling for rehabilitation when they come to Samarpan, but the practical aspect made him realize that home based rehabilitation in the rural context is a distant dream.

Though worried, Wankhede was not deterred with the aforesaid issues. He was confident that the system can be fine tuned to overcome the obstacles but it became really difficult for him when the issue came to treatment and rehabilitation of critical and complicated cases as he had no clue as to how tertiary level intervention for treatment and rehabilitation pertaining to developmental delay or disability would be done at the district level. In fact, he only had the facility of Composite Rehabilitation Centre (CRC)<sup>10</sup> located 125 km away from district headquarter at Bhopal, the state capital of Madhya Pradesh. The question again was as to how a link between his district will be made with CRC and other such institutions at Bhopal.

Chaos prevailing at the centre during the first month of the roll out, notwithstanding, Wankhede was all the more determined to iron out the issues which presented themselves during the execution. Going back to his office every day after the visit, Wankhede would jot down the practical problems that he faced and would stick it on notice board in his office. While discharging his duties, he kept on coming back to the problems and mentally worked on how best these can be sorted out. Wankhede was confident that he would be able to sort out all the issues, but it has been a year now that the Samarpan has been introduced by him, in which he was now greatly personally involved. The greatest advantage he had was the unquestionable and undivided support of his colleagues in the district as Samarpan was now everybody's programme and not that of District Collector's alone or of any single department.

The practice of meeting and having open discussion on Samarpan immediately after every TL meeting was continued throughout and Wankhede thought that it would be the best forum to discuss the way forward for Samarpan in light of the problems faced during the execution. It was decided that those AWWs who were too old to have further augmentation of capacity would be supported actively by their respective supervisors of

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<sup>10</sup> Composite Regional Centre for Persons with Disability (CPD) is a service modality set up under the Ministry of Social Justice & Empowerment, Govt. of India. The Ministry has set up 5 CRCs in different parts of India, one such CRC is located at Bhopal, M.P.

both WCD & Health department. Further, in such cases, the burden of screening and follow up would be more on the local ASHA workers rather than AWWs who would be assisted by Anganwadi Sahayikas<sup>11</sup>.

The migration issue was proposed to be taken care by preparing a dedicated work plan focussed only on migrant labourers. The suspected positive cases were supposed to be brought for their comprehensive evaluation at the Samarpan located in the district headquarter. It was also decided that free transportation from the doorstep to Samarpan and after examination, from the centre back to their home would be provided by the district administration through inter-departmental convergence of resources. A bus, which belonged to H&FW was repaired using funds of Red Cross Society. POL<sup>12</sup> for this bus was allocated through NNF of SJ&E and excess drivers, across the district were pooled up to provide services to drive this bus, which was effectively utilized for taking up the suspected cases along with their parents and local AWWs to Samarpan and back home. Just like the preparation of the route chart for election polling booth management, a route chart for taking up the suspected cases was proposed so that the travelling time is reduced and sector-wise children are brought to Samarpan in a systematic manner. Also, it was decided that no more than 30 cases per day would be brought to Samarpan from the sectors so as to minimize the waiting time under the multi-disciplinary approach.

Wankhede also appointed one of the staffs as manager of Samarpan and entrusted her with the task of coordinating with various multi-disciplinary experts working under the same roof and as also a link between government departments. In order to have clear and uniform format which will provide space for all disciplines to jot down their observations of a child, discussion with IPGMER<sup>13</sup>, Kolkata was carried out extensively. The association with IPGMER, Kolkata resulted in development of protocols, formats and training literature and it also laid a solid foundation for elementary community/home based rehabilitation.

A dedicated software for Samarpan was developed for monitoring, review and to make Samarpan a paperless institution. The problem of managing data of screening test of more than 1,50,000 U5 children in the district and its management was taken care of by using IT solutions. The problem of not having food and beverages at the Samarpan for the children as well as the staff was taken care by soliciting help from Rotary International free of cost.

Wankhede then started discussions on the treatments for development delay and disabilities which can be done at district level by having a convergence of inter-linking of sectoral programmes run by Government departments. For example, the National Programme for Blindness Control<sup>14</sup> has a provision of providing corrective glasses to young children. The active link was thus created to benefit the true positive U5 children, identified at Samarpan whose vision could be corrected by pair of glasses. On the same lines, by involving specialist doctors, minor corrective surgeries related to ENT, ophthalmology etc. were started at district hospital itself. For treatment of such delays and disabilities, which could not be taken care of at district hospital level, Wankhede

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<sup>11</sup> Every Anganwadi Worker is assisted by a helper, who is called Anganwadi Sahayika

<sup>12</sup> Petrol, Oil and Lubricants

<sup>13</sup> Institute of Post Graduate Medical Education and Research, Kolkata

<sup>14</sup> National programme for blindness control

spoke to various Head of Departments at Gandhi Medical College, Bhopal as also with the leading private medical practitioners in Bhopal and in the district so as to arrive at a protocol for treatment and rehabilitation of positive cases of children pertaining to development of delays and disabilities. For example, a tie up with CRC, Bhopal was done whereby tertiary level referral from Samarpan was done for positive cases identified at district level. On similar lines, tie-ups between other institutions having good background of tertiary treatment and rehabilitation in the field of disability was carried out.

A screening programme for early intervention of development of disabilities for children from birth to 5 years has never been tried earlier suo-moto by administration anywhere else in the country. Universal screening would lead to early detection of diseases, delays and disabilities resulting in timely intervention, ultimately leading to a reduction in mortality, morbidity and lifelong disability. Wankhede was very proud of the fact that Samarpan represents a paradigm shift as dividends of early intervention would be huge including improvement of survival outcome, reduction of malnutrition prevalence, enhancement of cognitive development and educational attainment and overall improvement of quality of life . He was a happy man but now he started thinking about Samarpan Plus, which would have facility of even tertiary intervention under a single roof. He had been lucky so far, as he had a stable tenure of more than three years as collector of a district. He knew that he has very limited time left in the district but undeterred, he started planning for Samarpan Plus.

## **PART - III**

### **Epilogue**

After initiation in 2010 and four rounds Samarpan SST on about 6 lakh plus U5 children, registered in ICDS in the district till July, 2014, about 17806 U5 children have been comprehensively examined at Samarpan, out of which, 1718 U5 children were identified as true positive.

The services which are being provided at the centre are psychological services, which include psychometric tests such as DASCII, DDST, MCHAT, BELEY etc.; speech and hearing services by audiologist through BERA and OAE, in addition to doctor speech software. An ear mould chamber has also been constructed to facilitate speech and hearing services. Further, comprehensive ophthalmological services including distribution of lenses and cataract surgeries; tailor- made artificial limbs and comprehensive physiotherapies; Neonatal neurological services in high risk newborns; occupational therapy services to promote self help skills, adaptive behaviour, adaptive play, sensory, motor and postural development; health care for promotion of optimum health and development by assessing health studies with anthropometry and growth assessment and immunization services and last but not the least nutritional promotional services by doctor and nurse and feeding problems and feeding practices are being provided at Samarpan. Samarpan Hoshangabad has been recognized as nodal referral centre for central India. As many as 12 different states/institutions have visited the centre so far for understanding the Samarpan model for replication .

Some of the important lessons learnt were that the capacity of human resources can be increased if they are imparted proper training. In addition, regular monitoring and evaluation of the programme is extremely important for success. Constructive criticism and role of media is important for institutions to foster themselves in standards of public service delivery. Rehabilitation of disability is a vast field and an ever expanding one, requiring constant appraisal, upgradation and adaptation and institutionalization of any model requires time and thus a proper hand-holding support is required in incipient stage.

Based on the success of Samarpan Early Intervention Centre at District Hoshangabad, Government of Madhya Pradesh decided to replicate the initiative at divisional level districts, eventually to be percolated to all the 51 districts of the state. Govt. of Madhya Pradesh also wrote to Ministry of Health and Family Welfare & Ministry of Social Justice & Empowerment, Govt. of India to replicate the initiative all across the country.

Overwhelmed with the success of Samarpan Early Intervention Centre, Secretary, Govt. of India, Department of Health and Family Welfare visited the centre at Hoshangabad in November 2011-12.

The District Collector, Nishant Warwade, was invited by the Secretary, Govt. of India, to give a presentation to Secretaries and Mission Directors of NRHM of entire country in Vigyan Bhawan, New Delhi. Consequently, a presentation by him was made to all the Secretaries and Mission Directors of all Union Territories and States of the country and serious effort to replicate it all across the country were thus started.

In March 2013, Ministry of Family Welfare & Health, Govt. of India launched Rasthriya Bal Suraksha Karyakram (RBSK), a child health screening and early intervention programme to provide comprehensive care to all the children in the community. The objective of RBSK is to improve overall quality of life of children through early detection of defects, diseases, deficiencies, developmental delays and disabilities. As per available estimates % of children are born with birth defects, 10 % of children are affected with developmental delays leading to disabilities. Various nutritional deficiencies affecting the pre school children range from 4 to 70 %. The screening and early intervention services is expected to cover more than 30 identified health conditions for early detection, free treatment and management through dedicated teams all across the country. District early intervention centres, based on Samarpan Hoshangabad, are planned to be set up as first referral point for further investigation for treatment and management. RBSK focuses on effective health intervention, which is intended to reduce both direct cost and out of pocket expenditure as also reducing the extent of disability and improving the quality of life and enabling all persons to achieve their full potential. It focusses on not only those new born and those attending Anganwadi Centre but also school going children and will ultimately benefit more than 27 crore children in the country. Additionally, provision of comprehensive child health care will also provide country wide epidemiological data on various diseases of children for future planning of area specific services.

Samarpan has been documented by the Centre for Innovation in Public Services (CIPS), Administrative Staff College of India (ASCI), Hyderabad in addition to documentations supported by UNDP.

The protagonist in the case (the then District Collector of District Hoshangabad, M.P) is presently posted as District Collector, Bhopal, capital of Madhya Pradesh who has now initiated Samarpan Plus at Bhopal as there is still no centre even at state capital which provides for comprehensive dissemination of information and services for treatment and rehabilitation for delays and disabilities under a single roof. Similarly, there is no one such institution where treatment and rehabilitation is offered for all types of delays and disabilities. Samarpan Plus aims to establish a resource centre which will address aforesaid questions and other related issues which exist.

Samarpan has achieved more than it had hoped for by facilitating a new policy where there had been a gap. Even though the implementation of the policy is in nascent stages, Samarpan Plus is already underway in Bhopal District. Samarpan Plus aims to learn from the challenges faced in Hoshangabad, especially the issue related to the tertiary links. Samarpan continues to direct policy intervention where there is a policy gap and presents an exciting field for policy makers and administrators alike.

## **PART - IV**

### **Way Forward**

Training of the personnel involved in child health screening and early intervention services is an essential component of the programme as it would be instrumental in imparting necessary information and skills required for child health screening and enhancing the performance of all the personnel involved in the health screening process at various levels.

A 'cascading training approach' will have to be adopted in order to ensure free flow of skills and knowledge at all levels and to maximize skill distribution. Standardized training modules/tools would be developed in partnership with technical support agencies and collaborative Centers as their technical knowledge and expertise will contribute to making the training process all comprehensive.<sup>15</sup>

An acute shortage of professionals, such as optometrist, audiologist, clinical psychologist, physiotherapist etc. who are well trained, is mostly commonly felt. A Capacity Building Training Centre(CBTC) with its apex at state level and branches at divisional and district level are, therefore, a must for increasing the capacity of not only professionals who are required for comprehensive screening but also for the grass root level workers who actually roll out the screening test as also officials of other related departments. These CBTCs will also double up as centre for dissemination of knowledge in field of early intervention and development delays as also a platform for spreading societal awareness. These CTBCs of states would eventually be linked to a super apex National Level Resource Centre ( NRC).

As far as practical, treatments to such delays and early identified handicaps, which can be done at secondary (district level), should be taken there itself and developed. For tertiary treatment and referrals, an institutionalized system of linkages through the state level and regional level CBTCs needs to be developed.

Apart from treatment and rehabilitation, some sort of vocational educational programme are to be thought of which can be linked with state level or the regional level training centre for critical cases so that not only they could avail treatment but also long term residential vocational education , resulting in increase in quality of their living and to that extent, decrease of the burden of disability on society at large. Block/AWCs/ Home based intervention coupled with a robust system of follow up has to be thought of and institutionalized. In other words, a model of serving the child near to their home with a family centered approach either at community level or at block level also needs to be established.

Early identification of various health conditions and assured link to care, support and treatment, under Comprehensive Child Health Care, introduces an equitable child health care approach. In the long run, early identification would help to reduce household expenditure of the poor and marginalized, reduce burden of diseases, build health awareness among people and also improve the professionalism in service delivery. Finally, this would lead to promotion of health among children, which is of fundamental value in and of itself.<sup>15</sup>

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<sup>15</sup> RBSK Operational Guidelines / Handbook for District EIC, RBSK.