

Technology Leveraged Early Intervention Project for Children with Developmental Delays - 9 blocks in Tirunelveli District

Submitted to

NUTANIX™

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Submitted By

S. Sankara Raman
Promoter Co-Chairman and Secretary

Amar Seva Sangam

E-Mail: secretary.amar@amarseva.org

Cell: +91 93610 11585/ 99444 54170



AMAR SEVA SANGAM

10-2-163 Sulochana Gardens
Tenkasi Road, Ayikudy – 627 852. Tamil Nadu. India
Website: www.amarseva.org
Email Id: secretary.amar@amarseva.org



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Introduction

According to a recent UNESCO report, in India, 72% of 5-year olds with disabilities have never attended any educational institution. In Tamil Nadu, 23% of all children with disabilities aged 5-19 having never attended an educational institution, while 99.4% of all children attend school. Parents and caregivers of children with disabilities face higher demands than caregivers of children who do not have disabilities in India, because of financial difficulties, challenges accessing care, time required for caregiving duties, perceived and experienced stigma, discrimination in the community and/or within families, and the physical burden of care.

According to the WHO: "If children with developmental delays or disabilities and their families are not provided with timely and appropriate early intervention, support and protection, their difficulties can become more severe—often leading to lifetime consequences, increased poverty and profound exclusion."

But the key is to make these children access to schooling which depends on catching them young and providing them Early Intervention.



Two recent studies conducted in rural India gives hope to millions of preschool children and their caregivers by showing that providing access to early intervention services improves school enrollment and integration for children with disabilities and reduces caregiver burden and increases family empowerment.

The study was on the Enabling Inclusion Technological Solution and model of Early Intervention services sphere headed by Amar Seva Sangam in southern rural districts of Tamil Nadu.

A peer reviewed study that appeared in the November issue of the prestigious journal, Frontiers in Public Health, showed that school enrollment for children improved from 70% to 85% for those provided with early intervention. The study also showed that caregiver-child therapy visit attendance significantly improved over time, from 60% to 95%, indicating caregiver recognition of the benefits of early intervention. The 2017



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study was conducted over a period of 2.5 years in areas where the Enabling Inclusion was implemented included 1050 children and their parents.

The Enabling Inclusion solution is to make the Early intervention reach the homes of the children by using the GPS mobile technology which enables community rehab workers to perform therapy sessions to children by connecting them with rehab professionals and train the parents. It is an end to end digital case management system which ensures quality services are delivered and monitored on real time basis at affordable cost.

The innovation is a breakthrough as it provides EI services to children by the parents in their own homes by mobilizing and training local women in the community to act as community rehabilitation workers to facilitate EI services by connecting them with rehabilitation professionals using our mobile app.

It is Awarded as one of the 30 best digital innovations in social sector for the year 2020 bisping and Anne February this year from The United Nations zero project at Vienna along with the mat solve global solution award in September 2019. Our innovation is a paradigm shift from therapists-centered to family-centered, center-based to home-based, individual-owned to community-owned and from high-cost to cost-effective.

We have reached 9,310 CwDD and their families and have screened 2,45,697 children for delayed development and reached 19,95,011 people in the community through awareness programs (Source <https://earlyintervention.amarseva.org/>). Our results have shown 87% visit attendance, leading to improved child development. 73% of families have shown greater empowerment and 74% have shown decreased strain using validated tools and there has been an age-adjusted increase in school enrolment for CwDD from 70% to 85%.

This project proposal is submitted to you will directly facilitate the Children with developmental delays and disabilities under Early Intervention programs in 9 blocks in Tirunelveli District of Tamil Nadu for one year as per the details given below:

Total INR – 1,01,25,246

No. of children

900

Average Cost per child per year

INR 11,250

Location

9 blocks in Tirunelveli District



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1. Project Concept

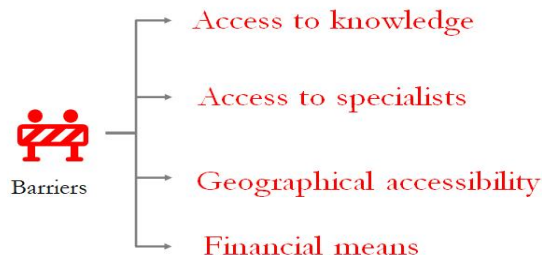
a) The Big Problem

According to a recent UNESCO report, in India, 72% of 5-year olds with disabilities have never attended any educational institution.

In Tamil Nadu, 23% of all children with disabilities aged 5-19 having never attended an educational institution, while 99.4% of all children attend school. Parents and caregivers of children with disabilities face higher demands than caregivers of children who do not have disabilities in India, because of financial difficulties, challenges accessing care, time required for caregiving duties, perceived and experienced stigma, discrimination in the community and/or within families, and the physical burden of care.

More than one hundred thousand children with developmental delays in Tamilnadu require Early Intervention services. About 67% of children live in rural and semi-urban areas in Tamilnadu. Where such no services available.

b) Root cause of the problem



c) Need for Early Intervention

According to the WHO: "If children with developmental delays or disabilities and their families are not provided with timely and appropriate early intervention, support and protection, their difficulties can become more severe—often leading to lifetime consequences, increased poverty and profound exclusion."

d) Our Solution

Enabling Inclusion® is a Digital platform that puts together the various rehabilitation protocols and program management that

- Reaches 4 times more the number of children for the same amount of investment
- Achieves 8 times more school enrolment at pre-primary level
- 73 out of 100 involved families gets improved social economic development



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Special Features

- Support NGOs, Government Department. Rehab centre and Professional
- Delivers high quality program with a high level of fidelity
- Reduces the dependence on Rehab Professional
- Enables the parents and community workers to get trained and deliver the services to the children
- Significantly reduces the cost
- Substantially increases the therapy compliances and parent child engagement

Innovation







- Technology Leveraged approach
- Developing a large, trained Community Rehab. Workers
- Reaching children at their doorsteps
- Enables community workers to connect with specialists and parents
- Provides individual care through real time exchange with the mobile technology
- Our model has high impact and is **highly scalable**

Amar Seva Sangam’s (our NGO) solution is to provide therapy for children in their own homes through Community Rehabilitation Workers (CRWs). CRWs are guided and monitored by rehabilitation specialists through an app we have developed called mobile Village Based Rehabilitation Enabling Inclusion ®.

This solution can be adopted globally as it helps overcome the lack of availability of rehab specialists in rural areas and leverages technology to connect community workers to specialists to provide therapy in a child’s own home.

e) Big Impact

IMPACT

 245697 Children Screened	 9310 Children received services	 26773 Parents Empowered
 13775 Workers Trained	 1995011 People Sensitised	 2272 Assistive devices prescribed

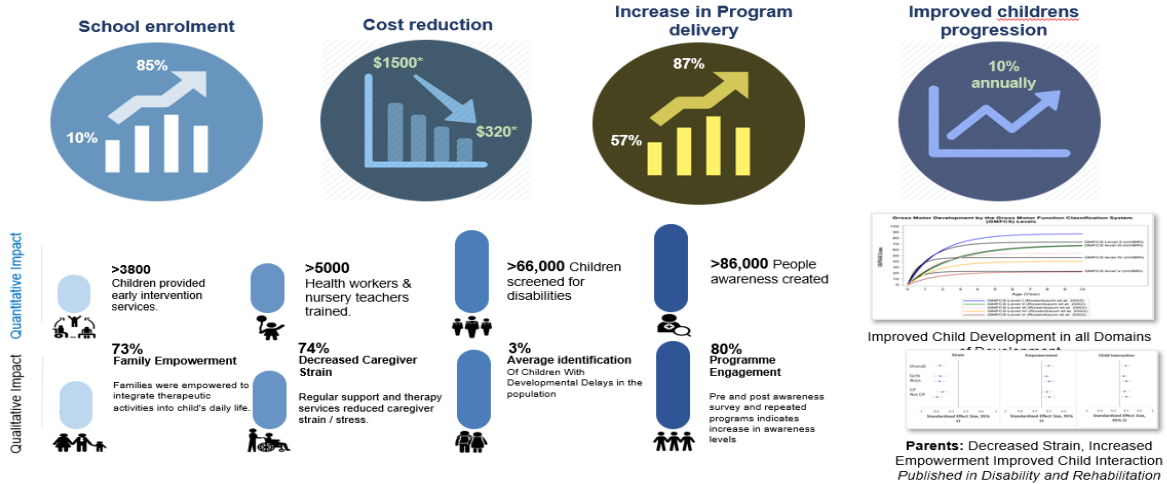


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Program Achievement and Impact



i. Key Takeaways

- Our model Enabling Inclusion powered by Enabling Inclusion® App is a high impact, family centered and community participatory solution.
- The family centered approach positively impacts the social and economic situation of parents resulting in 95% parent engagement, 73% families empowered, 74% decreased strain and functional improvements of the child
- The App uses GPS technology for real time tracking ensuring high therapy compliance (95% compliance rate)
- Trained CRWs deliver the services connected with Rehab professionals through the App resulting in 75% cost savings.
- Awareness programs deliver a community participatory approach (85% school enrolment up from 10% for CwDs)
- The standardized protocols built into the App generates comparable data across various parameters for active decision making, convergence, knowledge building, research and launch of large projects.
- "Role of the family is crucial in ensuring children survive and thrive" (Zuumond et. al. 2018)



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2. Background

a) About Amar Seva Sangam

Amar Seva Sangam is a premier organization in the field of disability management founded and run by **S Ramakrishnan, Padmashri awardee** and **S. Sankara Raman, a Chartered Accountant, both in wheelchairs**, with the zeal to create an **equal society**. Our focus is on rural areas. Our approach is to establish a centralized resource center and act as a Catalyst for change in the development of Persons with Disabilities by involving the village community in the process. We have built a strong team and infrastructure and deliver quality services at the local, regional and national levels.

We have successfully implemented several bold and innovative programs that caters to over 16,000 Persons with Disabilities in over 900 villages in different states in India by way of creating and scaling sustainable models for rehabilitation and development with high fidelity, high quality and high impact technology leveraged cost effective solutions, through collaborative approach with NGOs and government enabling them to become economically productive and join the mainstream society. They believe that disability is not a constraint but only a condition that can be managed. They aspire for a world where no child is denied schooling experience because of disability.

We are a globally recognized organization with several national and international **awards** including the President of India and the chief minister of the states on various occasions

Vision of Amar Seva Sangam

To establish a valley for the Disabled, whereby physically / mentally challenged persons live in a pro-active society where equality prevails irrespective of physical, mental or other challenged with the rest of the society. It is a futuristic vision whereby Amar Seva Sangam plays the role of an enabling agent to get the physically / mentally challenged "equality of status, equality in opportunities and equality in access". It is a society where people are identified as differently abled.

Mission of Amar Seva Sangam

To empower the disabled citizens by establishing a "Valley for the Disabled" as a Rehabilitation and Development Centre for the region and developing models for self-help initiatives by integrating the disabled individuals with the society for improved living conditions in the villages.



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b) What is Developmental Delay?

Child development refers to the process that children go through in skill development during predictable time periods called developmental milestones. Developmental delay occurs when children do not reach certain milestones by the expected time period. A difficulty in one area of development, such as speech, can influence development in other areas, such as socialization.

c) What is Early Intervention?

Early intervention is a set of rehabilitation methods to prevent the delay in the milestones becoming a functional disability for a child.

Kids develop skills in five main areas of development:

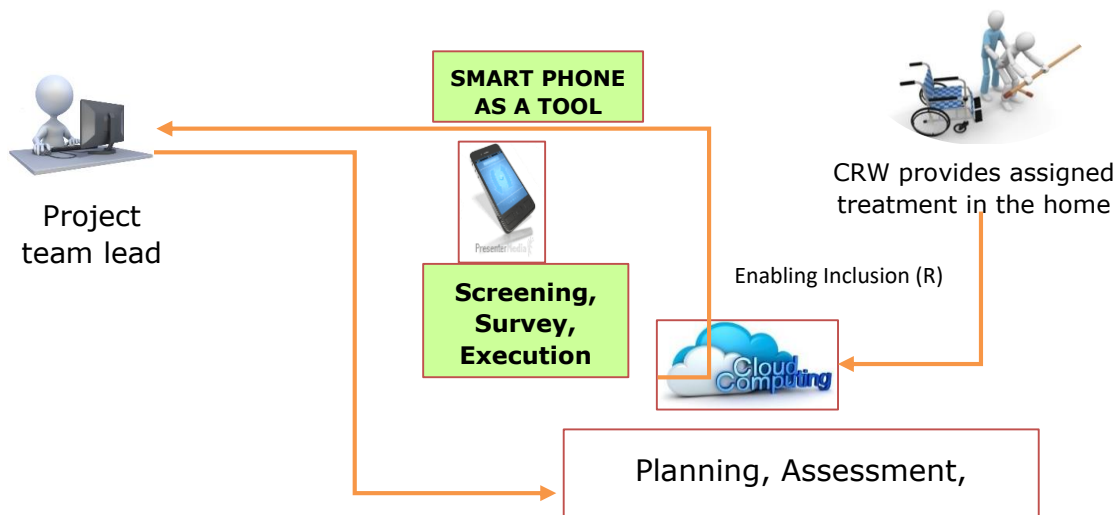
- *Cognitive (or thinking) skills*
- *Social and emotional skills*
- *Speech and language skills*
- *Fine and gross motor skills*
- *Daily living activities*

d) What is Enabling Inclusion?

Enabling Inclusion® is a high impact, family centered and community participatory model for early intervention and child rehabilitation services using the Enabling Inclusion® app for end-to-end case management and rehabilitation solutions.

e) Core technology of Enabling Inclusion® EI® App Technical Features

The EI® app is available on android devices and has a web and mobile platforms which has an off-line mode, so that data entered can be synced when internet is available. The EI® app follows Indian and GDPR data security regulations and standards.





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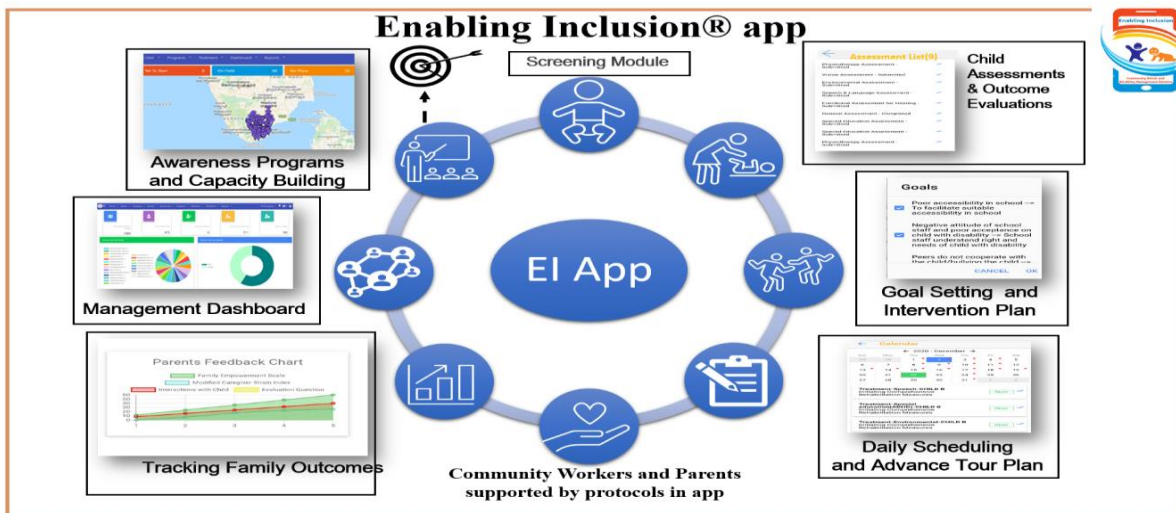
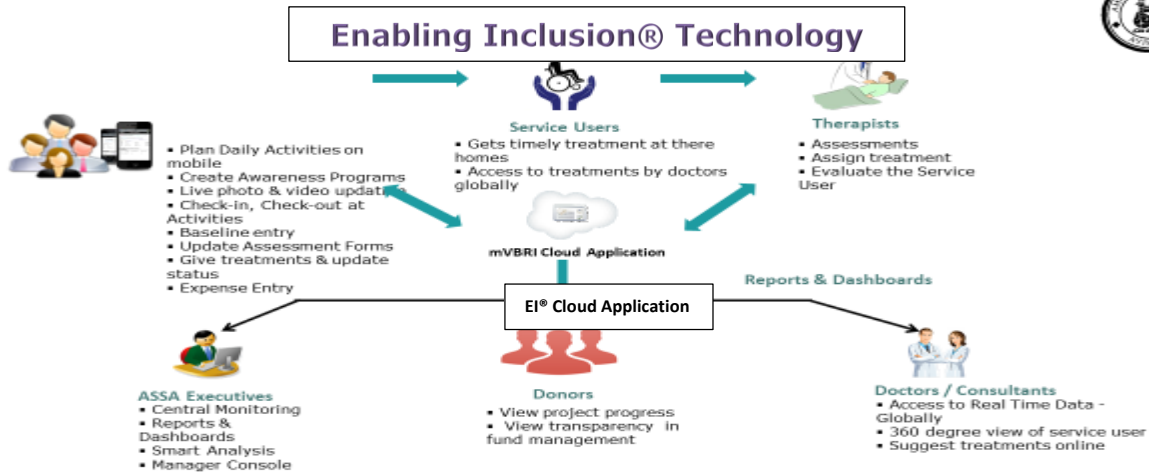
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Technology development





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3. The proposed Project

a) Project Title

Technology Leveraged Early Intervention Program for Children with Developmental Delays and Disabilities in 9 Blocks in Tirunelveli District.

b) Goal of the project

To promote therapeutic intervention to improve child development, functional level and participation of Children with Disabilities in 9 blocks in Tirunelveli District.

c) Objectives

- Early identification of developmental delay and disabilities among children
- Every Child with developmental delay and disabilities has access to early intervention irrespective of geographical location.
- Improved community awareness about developmental delay, intervention facilitation, rights and needs of children with disabilities

d) Programme Methodology

We hire and train local women in the community to become Community Rehabilitation Workers (CRWs) through a 2-week intensive training program.

All children in our surrounding community age 0-6 are screened for developmental delays in primary health centers and nursery schools by our team of CRWs and village health nurses, using a validated tool in our EI® app.

Children that are screened positive for delayed development are assessed by a multidisciplinary team of rehabilitation specialists (physiotherapists, occupational therapists, speech therapists and special educators) who provide a diagnosis and input their findings into the EI® app and set specific treatment goals and therapeutic protocols to be followed.

These children are enrolled free of cost into the program and CRWs follow the therapeutic protocols set by the specialists and provide therapy in all domains of development including physical, speech, cognitive and functional and provide support and coaching to parents. Therapy is provided by CRWs once a week in a child's own home and by parents for rest of the days.

Rehab specialists visit each child once in a month through joint visits with the CRW where they not only provide therapy for their child, but also provide expert guidance to CRWs and parents.

Rehab specialists review progress of children with standardized developmental tools (for gross motor, cognitive, self-care, mobility, speech) embedded in EI® app and re-input new goals and therapy plans every 6 months.

CRWs can communicate with specialists regularly to problem solve any issues in a child's therapy. They share videos and photos of the child or even do video conference with rehab specialists if need arise.

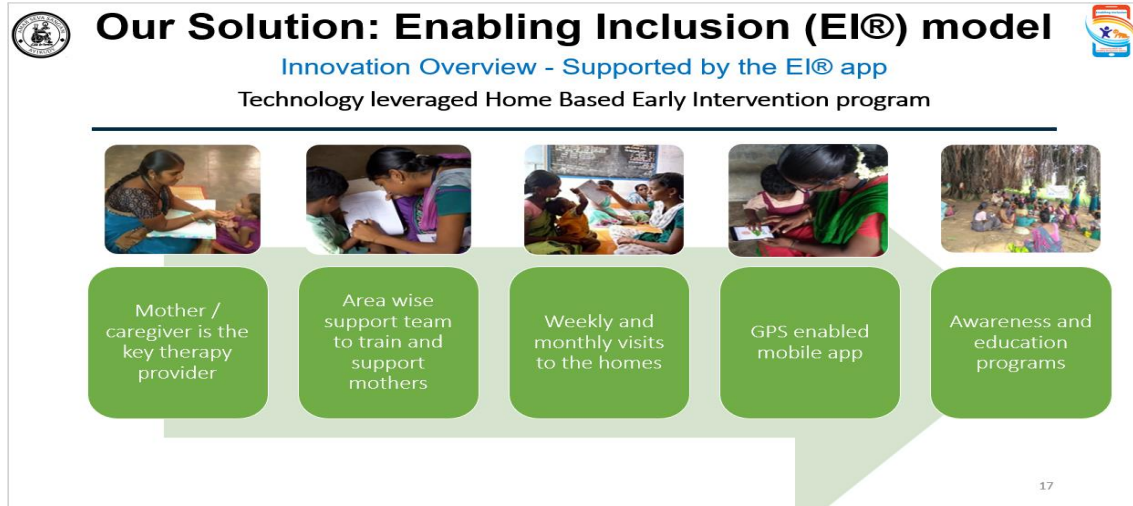


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The EI® app has GPS connectivity with which travel and therapy timings are monitored by the management team.



Focus on family centered therapy helps families to set goals for their child using the Canadian Occupational Performance Measure and family outcomes including caregiver strain, empowerment and child-parent interaction are measured every 6 months using validated tools.

Community awareness programs are conducted for schools, women and public by way of workshops on child development, disability, and gender and child disability rights.

Training programs are provided for CRWs, rehab specialists and parents. In addition to initial CRW training, 10 day workshops are given every 6 months to enhance their skills. Continuing rehab education opportunities are provided for rehab specialists. Parent empowerment and training workshops are conducted every 6 months.

4. Programme Process of implementation

a) Screening

The screening module within the EI® app has internationally validated screening tools including the UNICEF / Washington Group Module and the Trivandrum Development Screening chart which can be used by community workers and teachers to screen for developmental delays or disabilities. Once screened positive, there is an option in the EI® app to enroll children into the Enabling Inclusion® therapeutic and educational program.

b) Child Assessments and Evaluations

Children are initially assessed by community workers through a general assessment in the app which captures child and family demographic information and also all relevant child developmental, education and health information through parental interview. The General Assessment follows the WHO's International Classification of Functioning, Disability and Health (ICF) model covering body structure and function,



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activity, participation, environmental factors and personal factors. In this assessment, the developmental impairments identified in a child are selected by the community worker using a drop down selection which includes physical, cognitive, speech and language, hearing, vision and behavioural impairment. Based on these selections, the EI® app auto-assigns specialized assessments and evaluations to the relevant rehab specialists working in the program or the organization ecosystem which could include physiotherapy assessment, speech & language assessment, functional hearing and vision assessments and special education assessment (which includes ADHD, specific learning impairments and autism screening tools), amongst others. These assessments can be assigned to a physiotherapist, special educator, occupational therapist, speech therapist / trainer, psychologist or social worker, depending on the cadre of specialists in the program.

c) Family-Centred Goal Setting and Intervention / Therapy Planning

In the general assessment, a primary impairment is selected. This triggers a primary rehab specialist to be assigned. This primary rehab specialist then performs an environmental assessment, to allow them to better understand the home, family, community and school environment of the child and the existence of barriers to participation and inclusion that need to be addressed. The COPM (Canadian Occupational Performance Measure), a standardized tool, is used with families to identify their priorities and set functional and educational goals for their child. Based on these goals, each rehab specialist involved in the child's care selects the therapeutic goals and intervention plans in all relevant domains of development using drop down selections in the EI® app for the intervention period (usually 6-12 months) for both home and school based interventions. The COPM is also repeated at 6-12 month intervals to review goal achievement and set new priorities and goals.

d) Intervention Assignment and Therapy Scheduling and Monitoring

The interventions are then assigned to community workers and the child's primary teacher. Based on consultation with families, the home interventions / therapies are scheduled using the EI® app on particular days of the week or particular dates for the next 6-12 months and assigned to individual community workers. This schedule then appears on the calendar of these workers in their EI® app. Similarly, teachers are assigned certain interventions to do with that child in the classroom at set intervals. For every activity that community workers and teachers are assigned, they have to check-in at the beginning of the activity and check-out at the end and this is captured via GPS coordinates. This ensure the completion of activity and location of activity completion can be monitored by the program management and tracked to ensure fidelity.

e) Dashboard and Reporting

The Dashboard provides each user of the EI® app with a bird's eye view of the program, including the number of children under their care and their details including their disabilities. It also provides an overview of their intervention task assignments, their task accomplishment rate, etc. The management dashboard provides a



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comprehensive overview of the entire program including total children impacted by the program, total active children receiving services, children on wait list, children discharged, caregivers impacted, number of service providers, task assignment completion rate, children screened, number of positive children identified, school enrollment of children in the program and status of various program outputs (ie number of pending assessments, evaluations that were assigned). The dashboards have drill-downs, so clicking into any category will give you a detailed breakdown. The EI® app also flags children and families who are having worsening outcomes on any of the various child development and family outcome measures, so they can be identified for further follow-up. The EI® app collects a multitude of data and through the power pivot reporting features, reports can be generated for any data query and can be exported into Excel.

5. Program Outcome

This project will benefit 900 Children with Developmental Delays / Disabilities in 9 blocks in Tirunelveli District for one year.

Beneficiary*	Category*	Projected number*	Male*	Female*
Screening of all children in age group of 0-12 years in Maharashtra (38 screening program*40 children* 9 Block)	Direct	13,680	6,840	6,840
Children with disability	Direct	900	450	450
Train the caregivers	Direct	1800	900	900
Community Awareness People (elders) (9 Blocks* 13 Program* 25 participants)	In Direct	2,925	1,463	1,462
Women Awareness Age group B/W 15 to 25 (9 Blocks* 13 Program* 25 participants)	In Direct	2,925		2,925
School Awareness Age group below 14 (9 Blocks* 12 Program* 25 participants)	In Direct	2,700	1,350	1,350

6. Result Frame work

Means of Verification

- Enabling Inclusion APP
- TDSC and Washington scale results.
- Pre-test and post-test, scores of training and awareness program
- Case studies, Photos and Videos
- Parents feedback forms



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Objective	Activities	Activity Indicator	Outputs	Indicator	Outcomes	Indicator
Early identification of developmental delay and disabilities among children	Screening of Children with developmental delays/ Disabilities	342 Screening Camp	No of children screened and no of activities	13,680 children will be screened for developmental delay	Children rehabilitated	% of children with improvements in developmental progress and functional independence
	Conduct baseline for every identified child to capture demographic details	900 Baseline	No of baselines created	900 new baseline will be created		
	Conduct assessment for each identified child and prepare an intervention plan	900 Children with disabilities assessed for rehabilitation plan	No of children to whom assessment and intervention plan created	<ul style="list-style-type: none"> 900 children have detailed assessment and intervention plan for at least one treatment cycle Percentage of children with goal setting and therapy plan as against children identified with disabilities and enrolled. 		
Every Child with developmental delay and disabilities has access to early intervention irrespective of geographical location.	Provision of Rehab services	% of actual visits as against planned visit by CRWs and specialists per child	No. of visits by CRWs and specialists per child	<ul style="list-style-type: none"> 30 visits per year (Visits will be adjusted on pro-rata basis) Calendar and tour plan assigned and complied. Staff wise, children wise and area wise therapy schedule compliance. 		
	Evaluation of progression	Two evaluations per year.	900 children will have at least two evaluation physical, cognitive, communication and ADLs, and their parents for	% of improvement as per various standardized tools like GMFM, WeeFIM, COPM, FACP, COM.Deall, Caregivers and parents feedback form,etc.,		



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Objective	Activities	Activity Indicator	Outputs	Indicator	Outcomes	Indicator
			preparedness to manage their child every 6 month			
Improved community awareness about developmental delay, intervention facilitation, rights and needs of children with disabilities	Conduct Community awareness program	117 community programs conducted	No of community people sensitized/no of sessions	2,925 common people will be receiving disability rights sensitization	% improvement in understanding of disability rights	% of people have good understanding about the rights.
	Conduct school awareness program	108 awareness program conducted	No of students and teachers sensitized/no of sessions	2,700 students will be sensitized through awareness program	% improvement in the understanding of disability rights	% of people have good understanding about the rights
	Conduct women awareness program	117 women awareness program conducted	No of women sensitized	2,925 women will be sensitized about healthy pregnancy, developmental delay and disability	% improvement in understanding of disability, healthy pregnancy and developmental delay	% of women have good understanding the cause of disability and intervention services

7. District Level Project - Program Structure

Staff Requirement	Numbers
Local Coordinator	1
IT assistant and office admin	2
Field team leader	1
CRWs- home-based	18
Special educators- home-based	5
Speech trainers -home based	5
PT- home-based	5
Total	37



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8. Budget

Budget	Apr 2024 to Mar 2025	Percentage
SALARY	72,24,708	71%
PROGRAM EXPENSES	10,26,000	10%
TECHNOLOGY COST	15,60,000	16%
TRAINING& AWARENESS	3,14,538	3%
Total Amount in INR	1,01,25,246	100%
Cost Per Child Per Year	11,250	

All values in INR.

*Refer to Annexure I for a detailed budget.

9. Conclusion

Our Project is CSR compliant and registered under MCA Reg. No. [CSR00000229](#) and eligible under the Health, Education, Skill Development, and Rehabilitation of the disabled category. We are a Registered Charity under Section 12A and 80G under Income Tax Act Reg. No. AAATA9099HE20214. We are also registered under Foreign Contribution Regulation Act Reg. No. 076030105 and eligible to receive foreign contribution.

Needless to mention, it is because of such philanthropic minded organizations such as you, we are able to fulfil our programs for the welfare of the Persons with Disabilities. Please continue your good cause which would encourage us to serve the society with much more vigour.

Looking forward to hearing from you soon.

Thanking you,



S. Sankara Raman

Promoter Co-Chairman and Secretary

[Amar Seva Sangam](#)

Mobile: +91 9944454170

Email: secretary.amar@amarseva.org



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Annexure 1 – Detailed Project Proposal

CATEGORIES	ITEM	QTY	UOM	Units	Unit Description	Rate	Apr '2024 to Mar '2025
SALARY	CRW	18	Number of CRWs	12	Number of months	12,106	26,14,896
SALARY	PHYSIOTHERAPISTS	5	Number of Specialist	12	Number of months	23,764	12,83,256
SALARY	SPECIAL EDUCATORS	5	Number of Specialist	12	Number of months	17,357	9,37,278
SALARY	SPEECH TRAINERS	5	Number of Specialist	12	Number of months	17,357	9,37,278
SALARY	IT TECHNOLOGY ADMIN	1	Number of Persons	12	Number of months	16,000	1,92,000
SALARY	FIELD TEAM LEADERS	1	Number of Persons	12	Number of months	25,000	3,00,000
SALARY	COORDINATOR	1	Number of Persons	12	Number of Persons	35,000	4,20,000
SALARY	Occupational therapist	1	Number of Persons	12	Number of Persons	30,000	3,60,000
SALARY	Accounts and Office Admin	1	Number of Persons	12	Number of Persons	15,000	1,80,000
PROGRAM EXPENSES	CRWs	18	Number of Persons	12	Number of months	1,000	2,16,000
PROGRAM EXPENSES	PHYSIOTHERAPISTS	5	Number of Persons	12	Number of months	3,000	1,62,000
PROGRAM EXPENSES	SPECIAL EDUCATORS	5	Number of Persons	12	Number of months	3,000	1,62,000
PROGRAM EXPENSES	SPEECH TRAINERS	5	Number of Persons	12	Number of months	3,000	1,62,000
PROGRAM EXPENSES	FIELD TEAM LEADERS	1	Number of Persons	12	Number of months	4,000	48,000
PROGRAM EXPENSES	COORDINATOR	1	Number of Persons	12	Number of months	3,000	36,000
TECHNOLOGY COST	Web Server Space Cost	1	Lumpsum	12	Web Server Space Cost	40,000	4,80,000
TECHNOLOGY COST	Tech rehab fees [LICENCE FEE FOR EI APP]	900	No of children	12	Number of months	100	10,80,000
TRAINING & AWARENESS	CRWs CONTINUING EDUCATION AND PROFESSIONAL DEVELOPMENT	1	Lumpsum	1	As per annexure 1	55,790	55,790
TRAINING & AWARENESS	CONTINUING EDUCATION FOR REHABILITATION SPECIALIST	1	Lumpsum	1	As per annexure 2	51,748	51,748



AMAR SEVA SANGAM

10-2-163 Sulochana Gardens
Tenkasi Road, Ayikudy - 627 852. Tamil Nadu. India
Website: www.amarseva.org
Email Id: secretary.amar@amarseva.org



CATEGORIES	ITEM	QTY	UOM	Units	Unit Description	Rate	Apr '2024 to Mar '2025
TRAINING & AWARENESS	PARENT EMPOWERMENT CONSULTATION AND KNOWLEDGE TRANSLATION	1	Lumpsum	1	As per annexure 3	2,07,000	2,07,000
PROGRAM EXPENSES	MONITORING AND EVALUATION TRAVEL COST	1	Lumpsum	12	Number of months	10,000	1,20,000
PROGRAM EXPENSES	OFFICE ADMIN AND OPERATIONAL EXPENSES	1	Lumpsum	12	Number of months	10,000	1,20,000
TOTAL							1,01,25,246
Cost Per Child Per Year							11,250