

# AMAR SEVA SANGAM -AYIKUDY

Early Intervention Program for Childhood with Developmental Delays



Presented by S. SANKARA RAMAN Secretary, Amar Seva Sangam At Saksham National Conference On Sop. 29, 2018 at Jaipur





# NEED OF THE PROJECT

#### Amar Seva Sangam – El on Tablet



The birth of a child is an exciting, life-changing event. A beautiful new baby comes to your house, family, and neighbourhood. It is a time for celebration. Family members look at the new child and wonder: Will he be a football star, will she be a famous musician, will he discover the cure for cancer, will she become President of India?

But what happens when this new child has a disability? What if there are health problems? What if, as time goes by, it seems as if the child isn't learning and progressing as quickly or easily as other children? In fact, there are many supports available for infants, toddlers, and preschoolers with disabilities, Services for very young children, from birth to the 5th birthday (and sometimes beyond), are called Early Intervention.

Early intervention is an effective way to help children catch up or address specific developmental concerns as soon as possible in their lives. Sometimes babies are born with a condition or special need that affects their development. Other times a condition is not apparent at birth, but over time parents and doctors begin to wonder if the child is developing appropriately. Early Childhood Intervention means finding specific ways to help a child become as functional as possible.



# NEED OF THE PROJECT

Amar Seva Sangam – El on Tablet

"In India the incidence of infant mortality is decreasing while the incidence of non-communicable diseases is increasing – major cause for disability"

Kumar, Roy & Kar, 2012

"Early intervention (EI) programs for children under the age of 6 with a developmental delay are vital to improving long-term function, including performance in primary school" WHO. 2011

"Disability is a major barrier to access to education in India, more than 2.9 million children living with a disability" UIS and UNICEF, 2015 "45% of children with disabilities in Tamil Nadu do not attend school compared to 3% of all children"

World Bank's 2009 Report



# NEED OF THE PROJECT

Amar Seva Sangam – El on Tablet

#### PROBLEM

#### "SOLUTION"

- "Early intervention remains inaccessible for most children in Tamilnadu due to
- Cost mother has to engage an attendant, difficult with low income
- > lack of services in the area only trained people are involved
- Transportation difficult to carry a child in the bus

Mothers are trained and enhanced by CRW. CRW are provided with a custom made 'TABLET' application called mVBRI to facilitate communication with rehabilitation Specialists (Physio therapist, Occupational therapist, Special educators and Speech therapists) located remotely so that EI therapy could be provided at home and remote centers"



# ABOUT AMAR SEVA SANGAM

We are a non-government organization (NGO) located in rural southern India in a little town named Ayikudi

Our mission : To empower the Differently Abled citizens by establishing a "Valley for the Differently Abled" as a Rehabilitation and Development Centre for the region and developing models for self-help initiatives by integrating the Differently Abled individuals with the society for improved living conditions in the villages



# OUR INITIATIVES AT AMAR SEVA SANGAM

Early Intervention Program for Children Integrated and Special Needs School

Home for Disabled Children

Village Based Rehabilitation

Spinal Cord Injury Unit

Vocational Training Program

Orthosis and Wheelchair Workshop



### EARLY INTERVENTION VILLAGE-BASED REHABILITATION INITIATIVE

Through this initiative, we are providing early intervention assessment and treatment in children's home or community

Children who require early intervention have a delayed development and/or a diagnosis of cerebral palsy, cerebral palsy with mental retardation, autism, spina bifida

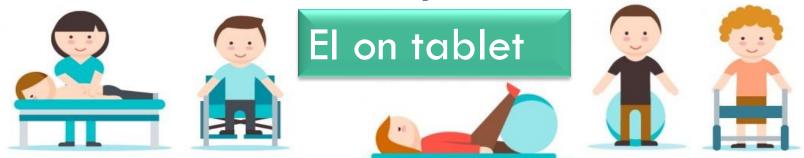
Early intervention includes physiotherapy, occupational theray, special education and speech therapy

Administering assessments and developing treatment plans are completed by rehabilitation professionals

The administration of the treatment plan is carried out by community rehabilitation workers (CRWs)

### Digital Health Solutions for Children with Developmental Delays......Amar

#### Seva experience



A Community Based Early Intervention Program at Home using mobile digital technology







# ABOUT MVBRI-EI ON TABLET

Village based Rehabilitation Initiative –Early Intervention

A Unique mobile enabled Village Based Rehabilitation Initiative program to provide Early Childhood intervention therapy to children below 6 years at their door step, covering more than 584 children, Screening New born babies and nurturing awareness on sensitizing, empowering and emancipating the disability in 599 villages in Southern part of Tirunelveli district of Tamil Nadu, India

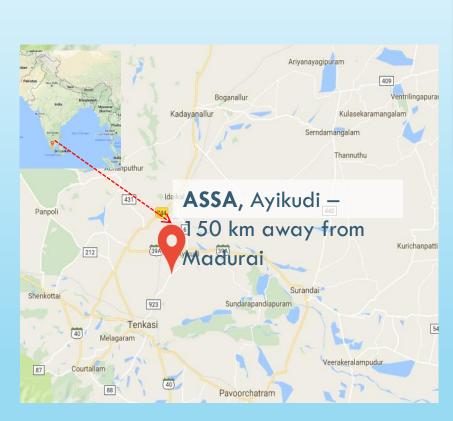
Providing Early Intervention therapy for children with delayed development, at home, free of cost, with the help of mobile Village Based Rehabilitation app

### **Our Location and Programs**

#### Amar Seva Sangam – El on Tablet











# Amar Seva Sangam – EI on Tablet

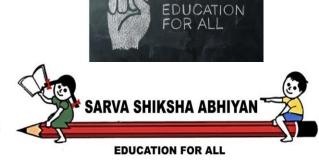




Grand Challenges Canada® Grands Défis Canada

BOLD IDEAS WITH BIG IMPACT®



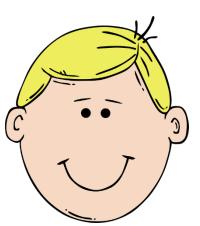


### WON LEADING CHANGE MAKER AWARD IN MOBILE FOR GOOD AWARDS 2016 Grant Thornton MASSCOM



Grant Thornton An instinct for growth







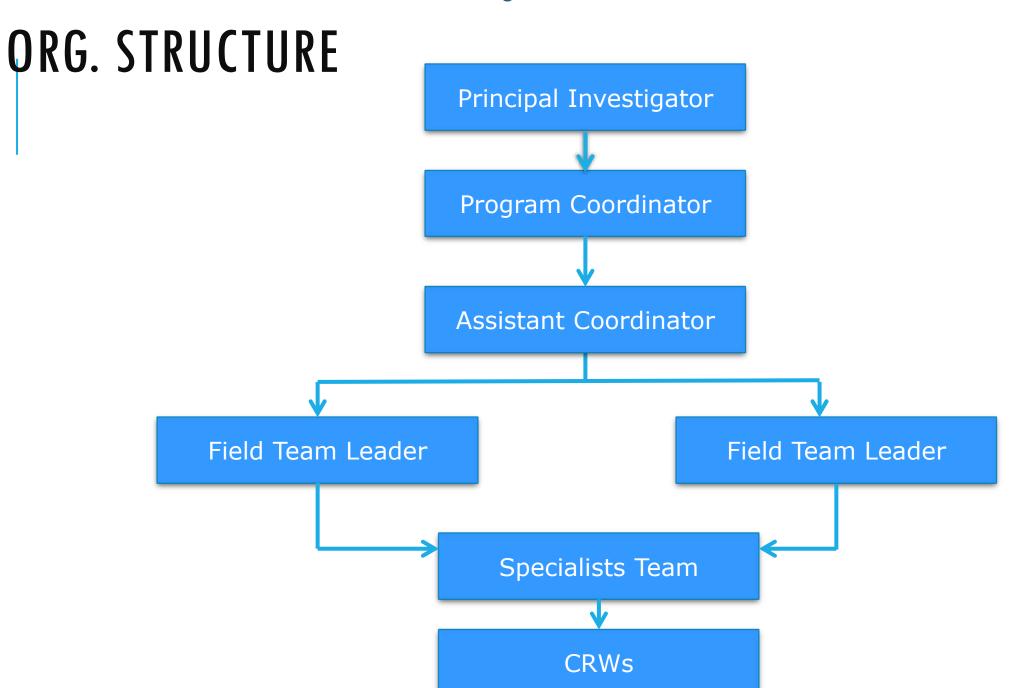
**TABLETS** 

**Connecting specialist** 

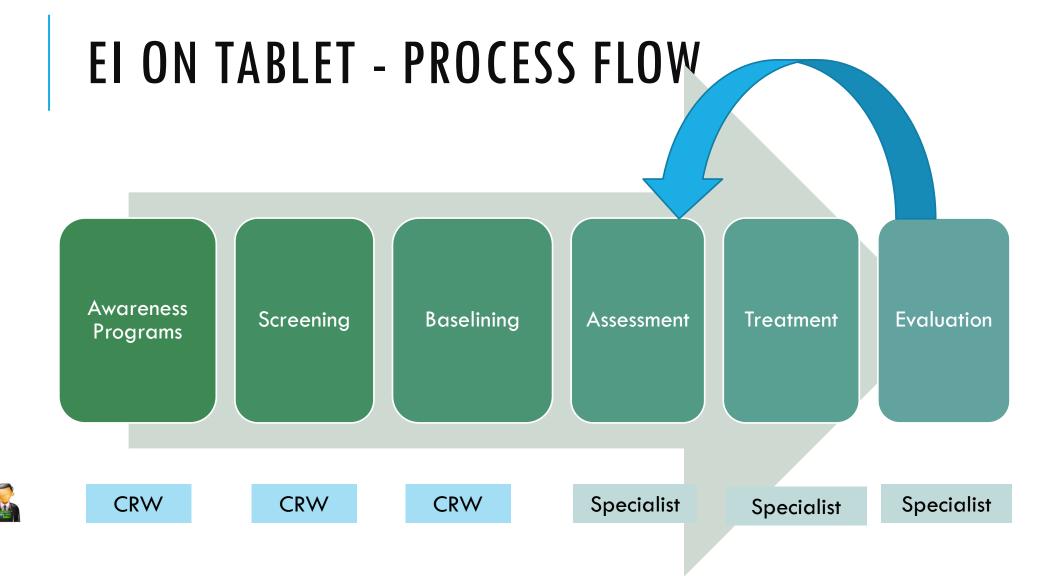
at 'ASSA and EI on Tablet'

mVBRI mobile application entered with Sales Force cloud application









### **ROGRAM LOGIC MODEL**

#### Program: Village-Based Early Intervention Program at Amar Seva Sangam

Inputs	Ou Activities	tputs Participation	Short	Outcomes Medium	Long
Staff 42 CRW - type 1 14 CRW - type 2 6 special educators 6 speech trainers 1 speech therapist 13 physiotherapists 3 occupational therapists 5 supporting staff members 1 co-project coordinator 1 assistant project coordinator 4 assistant project coordinator 1 assistant project coordinator 4 assistant project assistant project as	<ul> <li>Home-based early intervention therapy</li> <li>Early intervention parent participation centre based therapy</li> <li>Parent workshops</li> <li>Child development worker and community health nurse workshops</li> <li>Awareness presentations in the community</li> <li>Financial assistance, surgery referral and post-surgery follow up</li> <li>Screening programs and follow-up for high risks infants</li> <li>Continuing education for staff members</li> <li>Updates to the mVBRI application and software</li> <li>Dissemination of results through publications and conferences</li> </ul>	<ul> <li>Children with a developmental delay in 7 blocks of the Tirunelveli district</li> <li>Parents of children</li> <li>Community rehabilitation workers (CRWs) (ratio of 1 CRW : 12.5 children)</li> <li>Specialists : physiotherapists, occupational therapist, speech trainers, speech therapist, and special educators</li> <li>Child development workers and nurses</li> <li>Infants at high risk</li> <li>Awareness Programs : schoolaged children, college-aged youth and adults, pregnant women and women of child-bearing age, and general community members</li> </ul>	<ul> <li>Statistically significant improvement in children's developmental scores (within limits of their condition)</li> <li>Increase in therapy adherence rate</li> <li>Development of Early Intervention Parent Participation Centres</li> <li>Trainings provided to parents and/or caregivers, child development workers and nurses</li> <li>Awareness programs conducted in the community</li> <li>Development of education and therapy materials</li> <li>Updates to the mVBRI app</li> <li>Creation of employment for local women</li> </ul>	<ul> <li>Access to early intervention therapy for 700 children</li> <li>Increase in school integration of children with a developmental delay</li> <li>Parent participation in children's therapy and Early Intervention Centres</li> <li>Formation of parent groups for advocacy and income generating opportunities</li> <li>Creation of an early intervention therapy model and policy recommendations for early intervention best practices</li> <li>Paperless health records</li> <li>Program uptake by the Tamil Nadu government and/or other NGOs across the globe</li> </ul>	<ul> <li>Greater inclusion of children with a developmental delay within the community</li> <li>Better long term outcomes in the areas of intellectual, physical, mental, social and emotional well- being, leading to improved vocational opportunities and decreased dependence on state and others</li> <li>Better access to health services in rural and remote areas of Tamil Nadu and India</li> <li>Program taken u by Tamil Nadu Government</li> </ul>
	External Factors • "Education for A • Health and Educ • United Nations" • United Nations'	II' national Indian government p cation Ministries of Tamil Nadu Millennium Development Goals Convention on the Rights of Pe Convention on the Rights of the	rsons with Disabilities		and Challenges Canada ands Défis Canada are Intl.

#### Program: Village-Based Early Intervention Program at Amar Seva Sangam

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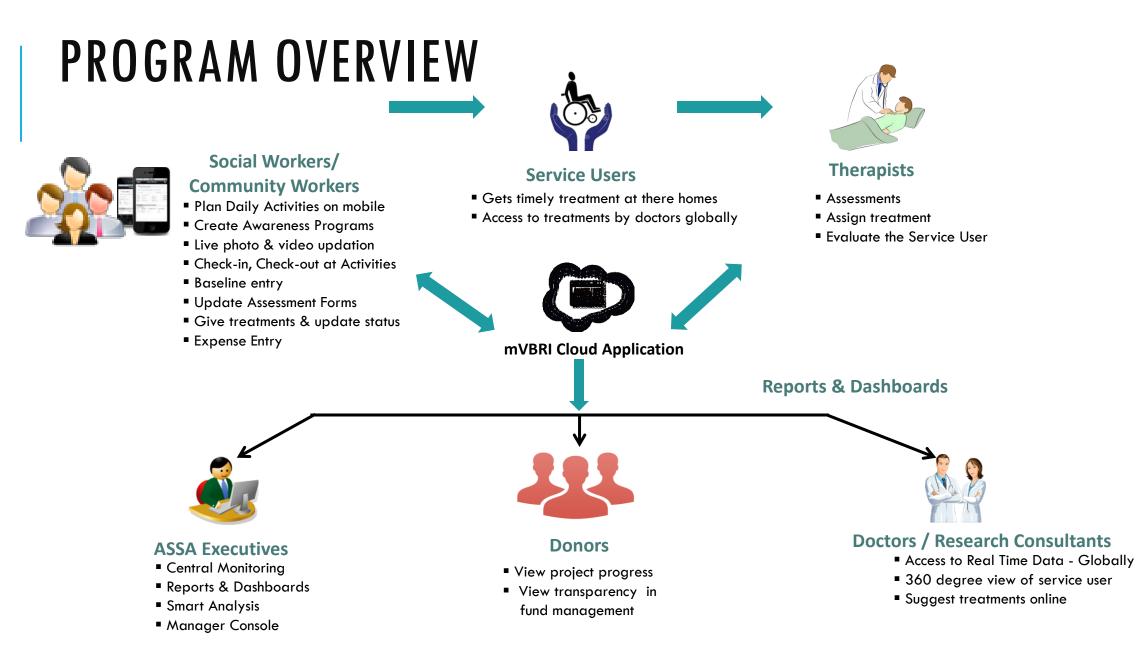
### EI ON TABLET — MVBRI APP. Mobile Village Based Rehabilitation initiative

A Mobile/Cloud Based Software Application developed and deployed to support VBRI program

#### Provides the following features

- Provides a system interface at every step From screening to evaluation
- Allows therapists to record their assessment and treatment plan
- Facilitates field workers to schedule and manage their daily routine
- Provides Field leaders a view of the work carried in the field
- Powerful dashboards to help manage the program
- Analytics to the management team and Research/Medical community
- Scalable solution using Android Tablets and Salesforce cloud







Amar Seva Sangam – El on Tablet

### EI ON TABLET — MVBRI APP. MOBILE VILLAGE BASED REHABILITATION INITIATIVE

#### THE FOLLOWING ARE THE ADVANTAGES:

- ✓ DELIVERY OF SERVICES AT HOME
  - MOTHERS GUIDED AND TRAINED
  - MUTUALLY CONVINIENT TIME FOR TREATMENT
  - WEEKLY VISITS BY COMMUNITY WORKERS AND MONTHLY BY SPECIALISTS
  - UNIFORM STANDARDISED TREATMENT IS FIXED BY SPECIALIST TEAM IN THE TAB, FOLLOWED BY THE MOTHER, REQURIED CONSULTATION THROUGH ONLINE BY PHOTOS OR VIDEOS
- ✓ TECHNOLOGY ENABLED
  - GEO NETWORK LINKS THE CHILD STAFF OFFICE
  - EASY THE OFFICE IN DASHBOARDS AND ONLINE DAILY REPORTS
  - DIRECT SYSTEM ENTRYMONITORING FROM
  - DIRECT AND DAILY ANALYSIS WHENEVER REQUIRED FROM ANYWHERE
  - EASY TO CARRY SMART PHONES WITH PRE INSTALLED SOFTWARES,
  - EASY TO COORDINATE THROUGH TELECONFERENCE AND TELE MEDICINE
  - E-MATERIALS, STORED IN TAB AND CLOUD, ECO FRIENDLY



# **SECURITY AND AUDIT**

Data Security

- Access using Login Id and password
- Multiple access types depending on user type

Salesforce provides multilayered security, primarily to control access

(Organization Security, Object Security, Record Security, Field Security and Folder Security

- Data Backup /restoration completely managed by Salesforce
- Mobile units hold limited data till they Sync with 'cloud'

#### **Application Security**

- Application resides in 'Cloud' and managed by Salesforce ensuring availability at all times
- Whenever there is a new release ,mobile units automatically download the version so that all mobile units will be on the same version .Units not on latest version is visible to adminstrator.

#### Audit facility

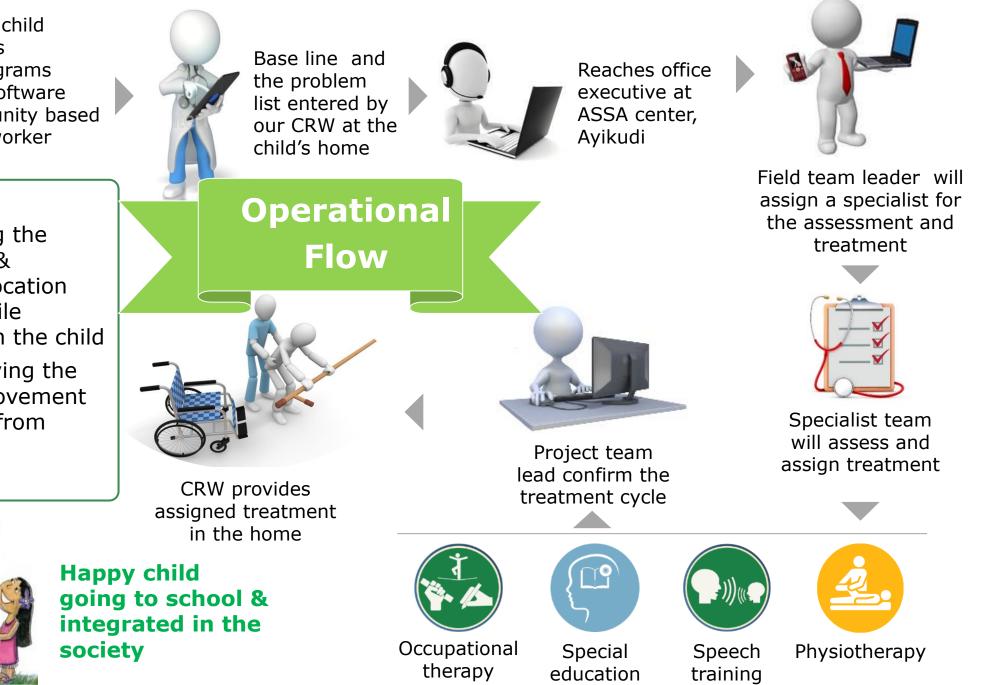
- Salesforce provides powerful audit facility to monitor and control security risks like
  - Login History, Setting Audit trails, Record/Field modification tracking etc.



# through various

Identifying the child awareness programs based on the software data by community based rehabilitation worker

#### Amar Seva Sangam – El on Tablet



- Tracking and guiding the CRW, social worker & Specialist by GPS location through "AMAR Mobile Application" to reach the child
- Monitoring & Observing the treatment and improvement of every child 24x7 from anywhere





# **REPORTS/DASHBOARDS**

- Operational reports for day to day management
- Evaluation reports to track child's progress
- Management control /Console
- Analytics to help determine problem areas and trends





#### Amar Seva Sangam – El on Tablet

### OUR EXPERIENCE SO FAR

#### OUTCOME

584 Number of children enrolled in the program and accessing therapy

8 Blocks (Geographical Areas) in Tirunelveli District Covered

271 children successfully enrolled and integrated in Pre School & School

4 Number of EI PPCs developed

76% Adherence to therapy rate (Home Based 90% & Center Based 62%)

1513 Number of people receiving Early Intervention training (e.g. : parents/caregivers, CRWs, social workers, village health nurses)

106 Number of jobs created

2 Number of innovative and/or service delivery models developed (Creation of the mVBRI app and development of a home-based early intervention program)

Improvement in Developmental Scores of Children 85%, 91%, 65%, 73% of children showed improvement in gross motor, occupational, cognitive and speech functions respectively.



Project in 8 blocks: Alangulam, Kadayanallur, Keelapavoor, Sankarankovil, Senkottai, Tenkasi, Vasudevanallur and Kadayam.

Early Intervention programme

- Home based rehabilitation: 685
  - In all 8 blocks
- Centre based rehabilitation: 104
  - 6 centres at Achanpudhur, Ambur, ASSA, Kadayam, Pavoorchatram And Surandai.
- Children identified and recruited for El programme.





### HOME AND CENTER BASED REHABILITAION











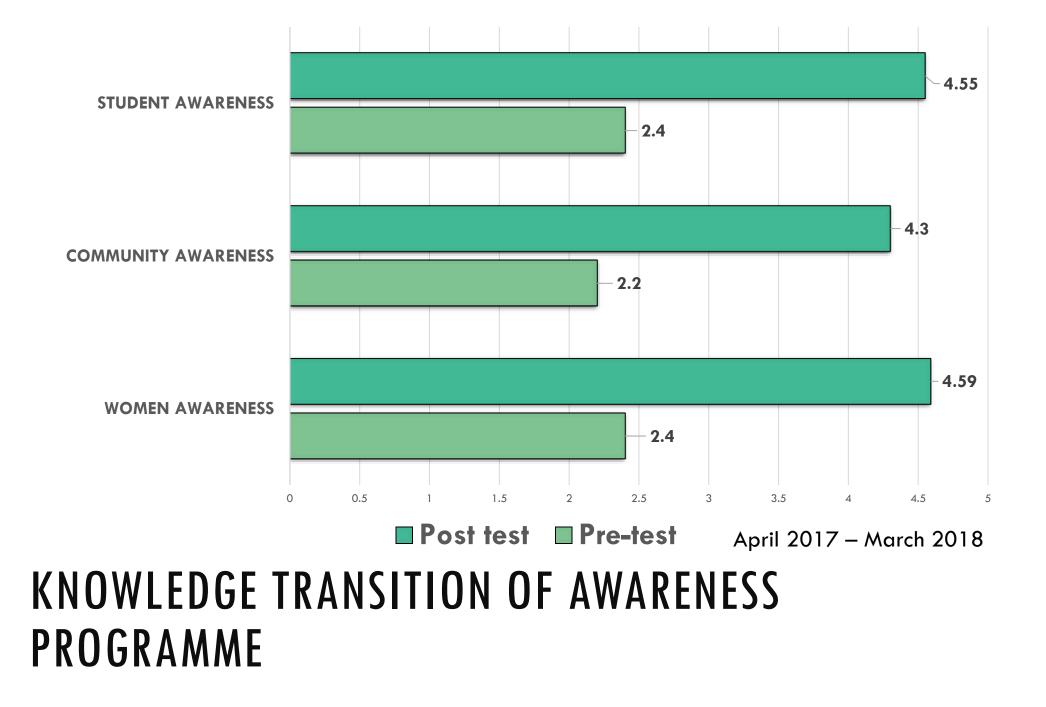


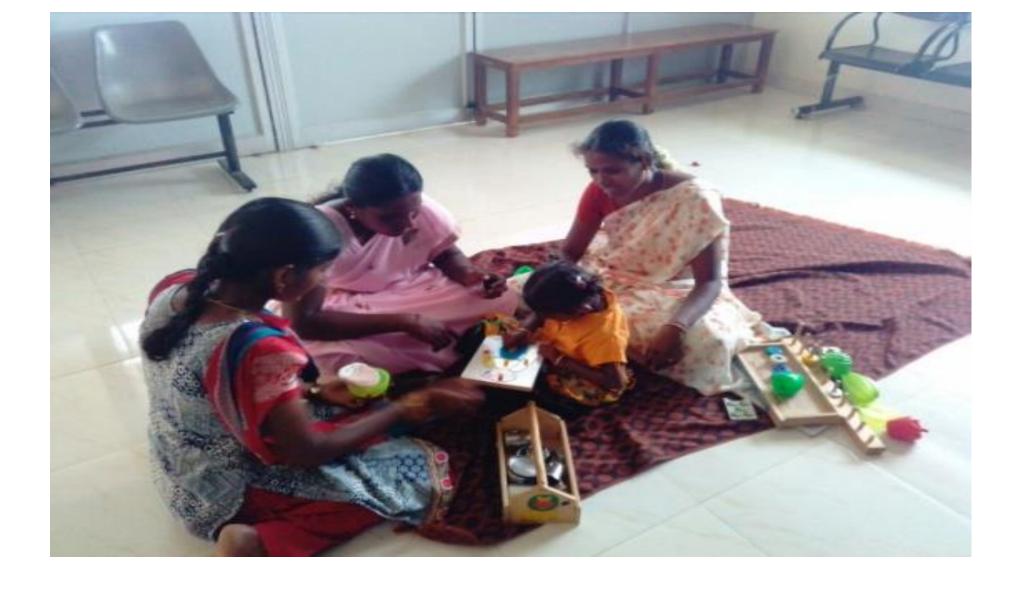
### **COMMUNITY AWARENESS** 4173 2400 **STUDENTS AWARENESS** 2580 6129 WOMEN AWARENESS 2580 4680 7560 14982 AWARENESS PROGRAMME (2017 APRIL - 2018 AUGUST)

TARGET

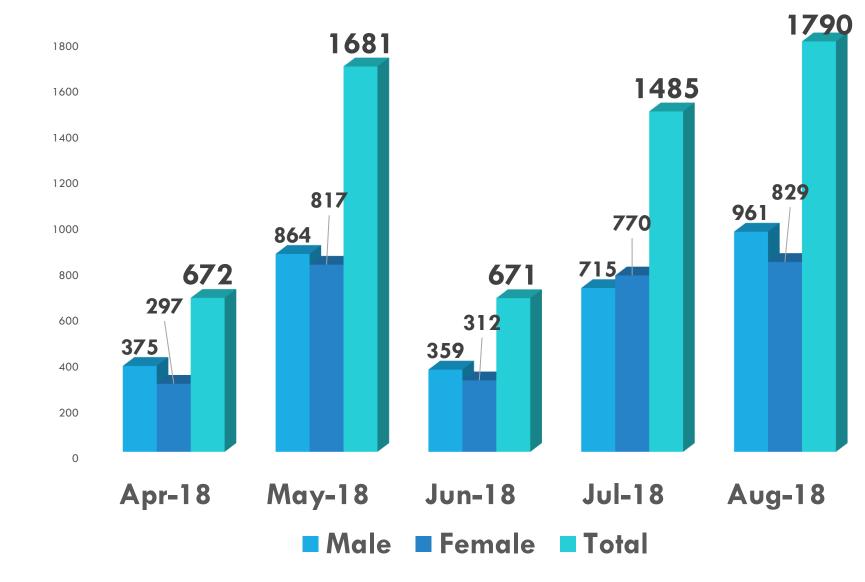
TOTAL

TITLE

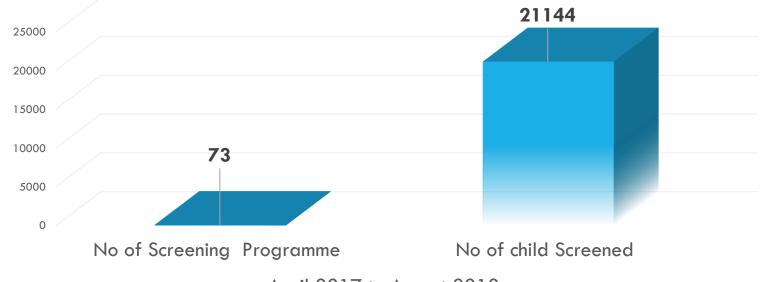




### **SCREENING PROGRAMME**



### SCREENING PROGRAMME (APRIL 2018 — AUGUST 2018)



April 2017 to August 2018

### SCREENING PROGRAMME (APRIL 2017 — AUGUST 2018)



### PARENTS TRAINING PROGRAMME



### PARENTS TRAINING PROGRAMME



- An exposure visit was organized on 10<sup>th</sup> of March 2018 to Kodaikannal for children and their Parents of VBRI Rehabilitation in 5 buses.
- Totally 401 joined with us.
  - 189 Children
  - 120 Parents

# EXPOSU<sup>2</sup>R<sup>t</sup>E<sup>ff</sup> VISIT

### Continuing Rehabilitation Education (CRE) Collaboration with NIPMED training programme





### SPECIALIST TRAINING PROGRAMME



• 7 anganwadi training programs and reached out 269 workers from 5 blocks in Tirunelveli District.

### ANGANWADI TRAINING PROGRAMME



# AWARDS AND ACHIEVEMENTS

El project proposal was approved by the Tamilnadu Ministry.

Grant received from UNICEF to Government to conduct the pilot study

Pilot study started at Namakkal and Madurai District

- Madurai 74 children
- Namakkal 13 children





# GOVT PILOT PROGRAMME. CRW TRAINING PROGRAMME







## **GOVT. PIOLOT PROGRAMME**







#### The training included

- Developmental milestones,
- Types of developmental
  - delay,
- Neuroplasticity,
- Using the TDSC,
- Using the mVBRI software to collect data on case identification,
- Introduction to what early intervention is and its benefits.

CASE IDENTIFICATION AND INTEGRATING THE DATA INTO SOFTWARE







PHASE	- 111

SPECIALIST TEAM OF SARVA SHIKSHA ABHIYAN IN TIRUNELVELI DISTRICT (EXCEPT ASSA WORKING AREA) The training included

Neuroplasticity,
Using the mVBRI software
for regular visits.
Implementing the Early
Intervention

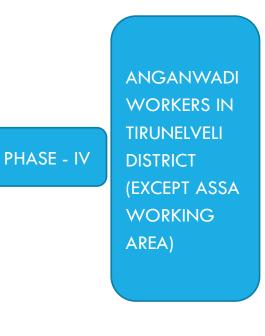
 Train the Anganwadi workers and Care givers of the children with delayed development
 Preparing the visit schedule

Structured Early intervention

and its benefits.

TRAIN THE ANGANWADI WORKERS AND PARENTS OF CHILDREN WITH DEVELOPMENTA L DELAYS IN THE HOME





#### The training included

- Early Intervention module of ASSA
- Using the mVBRI software for regular visits.
- Train the Care givers of the children with delayed development
- Preparing the visit schedule
- Structured early intervention and its benefits.

TRAIN THE PARENTS OF CHILDREN WITH DEVELOPMENTAL DELAYS IN THE HOME

IMPLEMENTING EARLY INTERVENTION





SUPERVISORY TEAM OF NATAIONAL HEALTH MISSION The training included Structured early intervention and its benefits. Monitoring aspects ofEarly Intervention module of ASSA using the mVBRI software for regular visits. Extracting and Report generation from mVBRI software. Analyzing the data

SUCCESSFUL IMPLEMENTATION OF EARLY INTERVENTION WITH DIGITAL TECHNOLOGY

TRAINING PLACE	DATE	NO OF BLOCKS	NO OF THE TRAINEES ATTENDED	PRE- TEST SCORE MAX(5)	POST- TEST SCORE MAX(5)
MADURAI, VILIPURAM, SALEM, CHENNAI	11 / 06 / 2018 _ 26 / 06 / 2018	385	558	2.06	4.83

## HM - RBSK TRAINING PROGRAMME HASE - I









#### **RESEARCH TIE Ups:**

- ICDR University of Toronto
- Kalasalingam University
- McGill University
- Queens University

Research approval obtained form Kalasalingam University Ethical approval obtained from University of Toronto and McGill Registered in International Clinical trial registry.

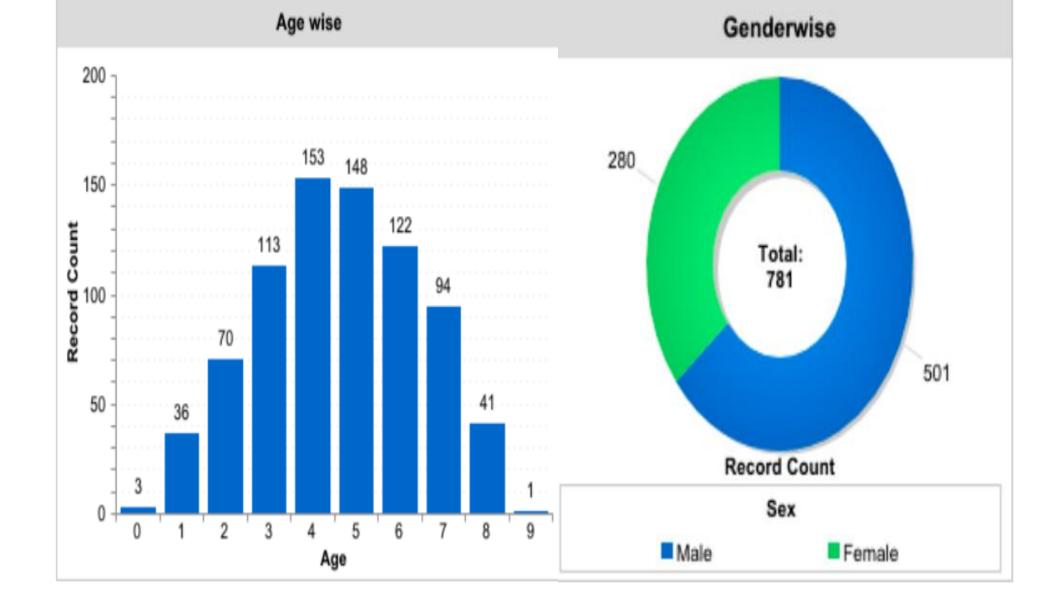
Initiated for ASSA Institutional Ethical committee – Registration in process

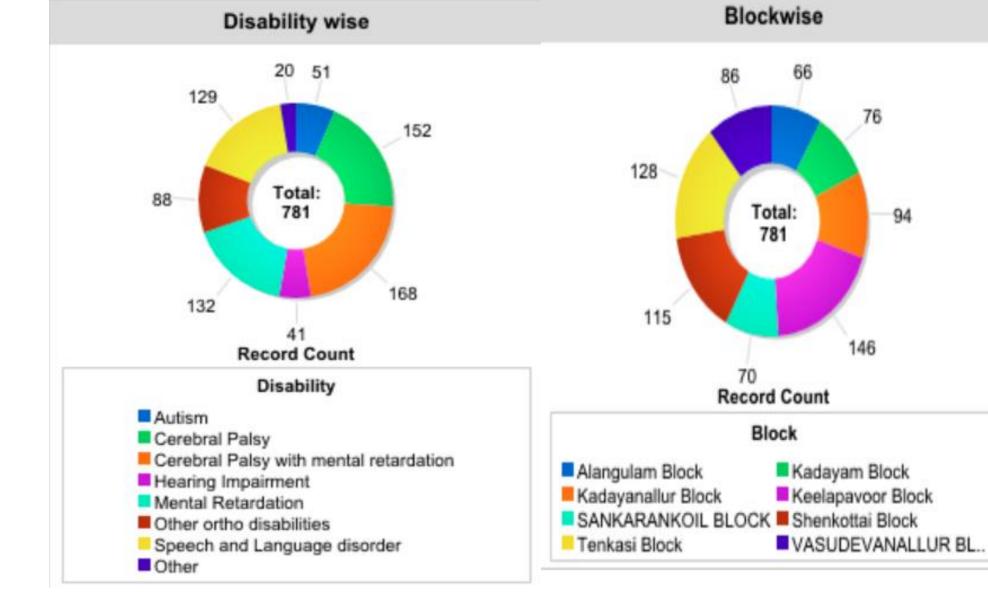


- Developmental Score Trajectory
- Treatment Compliance and Development
- School Enrollment
- Parent/Caregiver Change
- Prevalence study
- Awareness Training
- Training for Parents
- Community rehabilitation training for CRW, VHN, and ICDS
- Choaking hazards

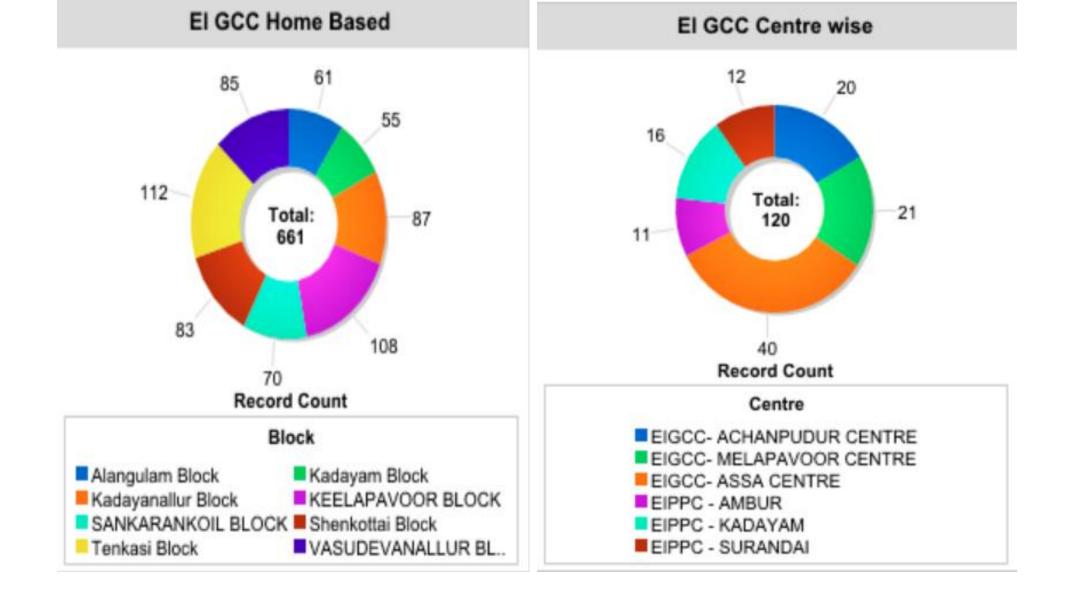


# AGE GENDER CATEGORY





# **BLOCK & DISABILITY**



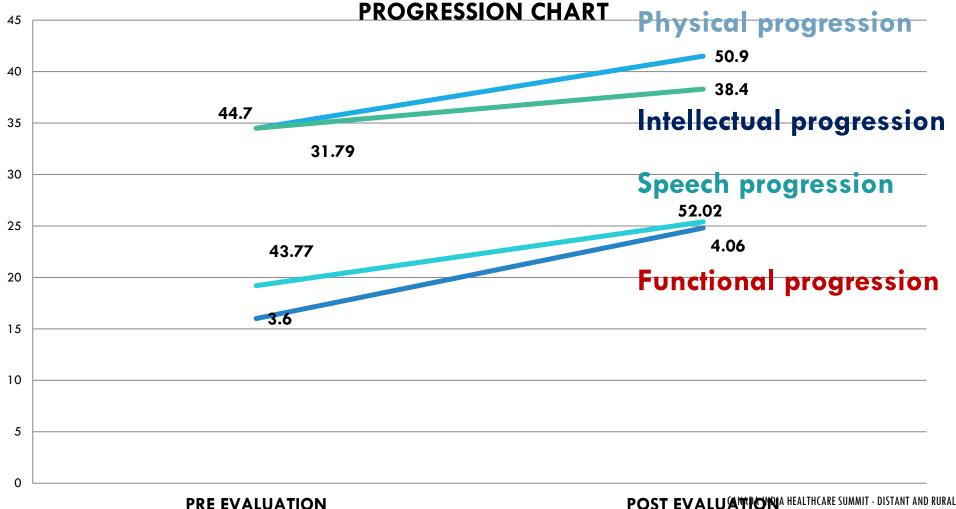
## REHABILITATION







### WHY MVBRI: "REHAB ON TABLET" ?



POST EVALUATION A HEALTHCARE SUMMIT - DISTANT AND RURAL CARE SESSION 54



# WAY AHEAD — AMAR SEVA SANGAM EI ON TABLETS

Provide analytical information so as to help 'Identification ' of disability apart from providing facility for correction

Provide 'collaboration' for scaleup.

Provide sufficient and meaningful data for research

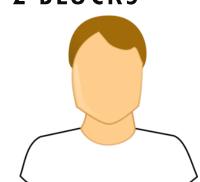




### WAY AHEAD - EI ON TABLETS **OPERATING TEAM** — 1 CLUSTER 2 BLOCKS









CRW (8)

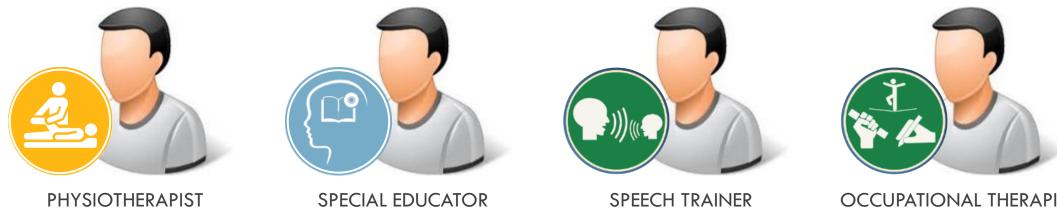


**EXPERT TEAM** 

160 CHILDREN

PROJECT LEAD

FIELD TEAM LEADER



OCCUPATIONAL THERAPIST

#### Amar Seva Sangam – El on Tablet

## Way Ahead — El on tablet Operating Team — 1 Cluster 2 Blocks

#### The project will result in

- 160 children getting rehabilitation
- 16 jobs created
- 320 care givers (parents or the relatives of the differently abled children) will be trained to care their children in a therapeutic manner.
- 1600 community member including Pregnant women, college students, and community dwellers will get awareness about the disability prevention and health awareness.
- 6000 New Born Babies will be screened for the high risk status

#### What is for Corporates

- CSR eligibility under Health
- Eligible to receive foreign contributions
- Registered Charity under Section 12A of Income Tax Act
- Donation eligible under Section 80G
- Organization registered under Tamil Nadu Societies Registration Act.



Amar Seva Sangam – El on Tablet

### Way Ahead — El on tablet Operating Team — 1 Cluster 2 Blocks

THE AMOUNT INVESTED

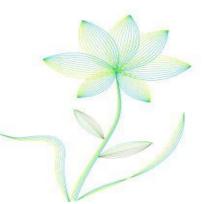
INR 4,964,000

TOTAL NUMBER OF CHILDREN

160

INVESTMENT / CHILD / YEAR









# Going Forward

Amar Seva Sangam would be proud to collaborate as a knowledge partner with the Governments, Corporates and NGOs For the scale up