Early Intervention App and Digital technology: Bridging the rehabilitation service gap in India

Franzina Coutinho[1,2], Dinesh Krishna,[1,3,4], Marie Brien[1], Paramakalyani Rajeshwaran[1], Navamani Venkatachalapathy[1], Gauri Saxena[5]

[1]Amar Seva Sangam, Ayikudi, Tamil Nadu, India, [2]McGill University, Montreal, Canada, [3]Handi-Care International, Toronto, Canada, [4]University of Toronto, Canada, [5]Inspirium Holistic

ICNC 2022
17th INTERNATIONAL CHILD NEUROLOGY CONGRESS
ANTALYA, TURKEY | OCTOBER 3-7, 2022

INTRODUCTION

Amar Seva Sangam Ayikudy (ASSA) is a unique non-profit, **non-governmental organisation in Tamil Nadu, India**. ASSA is intimately involved in various community initiatives and strongly believes that digital technology offers unique solutions towards bridging the healthcare divide.

Low and middle-income countries such as India are home to 95% of the world's children with disabilities (CWDs) under the age of five years, and 80% live in rural areas with no access to early intervention services. Barriers to inclusion of CWDs are stigma, lack of professional training, and limited services due to lack of funding.

In 2014, Amar Seva Sangam (ASSA), a disability NGO working in Tamil Nadu, India initiated the development of an innovative solution to support the rights of CWDs and their families.

ENABLING INCLUSION® APP

The EI® model is based on the principles of **family-centred care** and is implemented using a **community-based rehabilitation** strategy and is used with children between 0-18 years of age.

The EI model's integrated modules include:

(1) Validated screening tools
- TDSC (Trivandrum Development Screening Chart)
- UNICEF/Washington Group Child Functioning Module

(2) Assessment module
- General Child and Family Assessment;
- Discipline-specific assessments: physiotherapy, special education, speech, functional vision & hearing assessment
- Environmental Assessment: home and school environment,

(3) Standardized evaluations;
- GMFM (Gross Motor Function measure)
- Wee-FIM (Pediatric Functional Independence)
- Com-DEALL (Communication Developmentai Checklist)
- FACP (Functional Assessment Checklist for Programming)

**(4) Family-centred goal setting tool and caregiver measures;**
- COPM (Canadian Occupational Performance Measure)
- FES (Family Empowerment Scale)
- MCSI (Modified Caregiver Strain Index)
- CI (Caregiver-child interaction measure)

(5) ICF-based intervention activities: Treatment based on child and family needs and goals.
(6) Training and awareness module: Training for Child development / ICDS workers, Health Workers, teachers, parent groups. Awareness programs for community, women and student groups.

ENABLING INCLUSION® APP PROCESS

Enabling Inclusion® (EI) model Supported by the EI® app
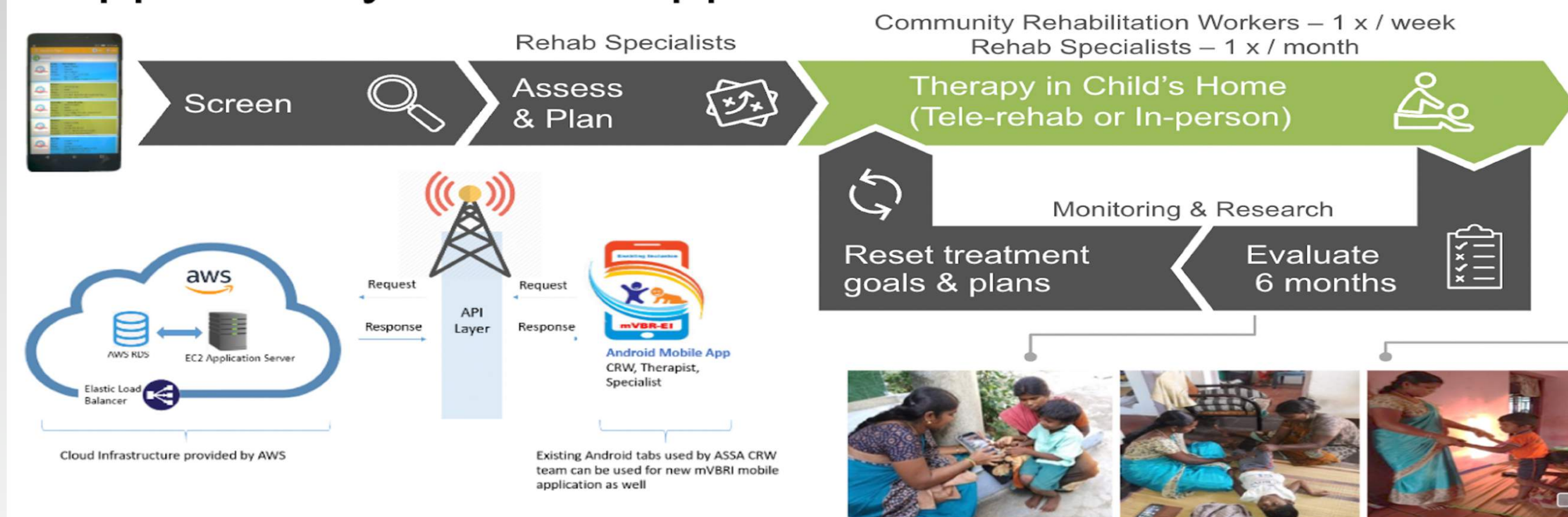
RESULTS

- The app is currently used in **5 states** in India. Overall, the EI® app has **screened 83,846 children** for developmental disabilities.
- **4,105 children** have **improved developmental outcomes** through individualized intervention plans as a result of this innovation since January 2015.

FIGURE 1:
Primary Disabilities Diagnosed And Provided Rehabilitation Services
(N=1700)

Primary disabilities diagnosed and provided rehabilitation services
- Intellectual Disability 314
- ASD 301
- CP 1085
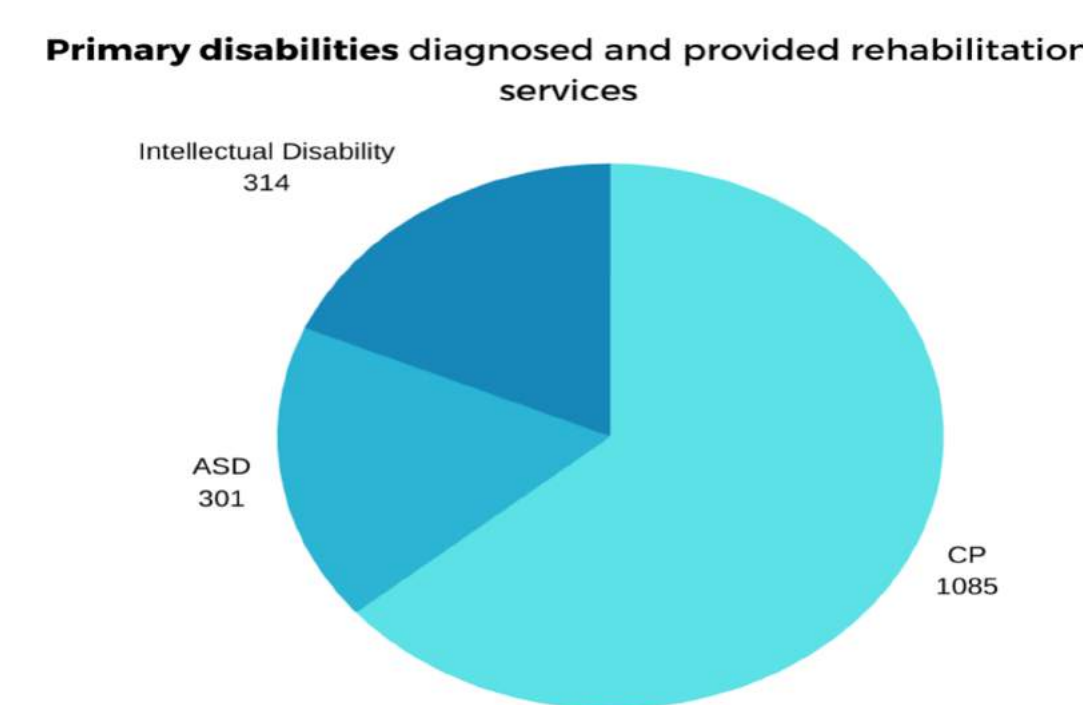
- Of these children , 2555 (62%) are male and 1395 (34 %) are currently enrolled in school.
- **5535 health and education workers** have been trained in identifying developmental disabilities and providing early intervention and child rehabilitation services as a result of the EI® innovation emphasized through caregiver capacity building (coaching approach), parent support groups, and peer mentorship.

CONCLUSIONS

Implementing digital technologies holds unique advantages for densely populated countries such as India. It allows for **improved communication** across all stakeholders, thus aiding the adoption of a transdisciplinary approach across geographical lines.

The EI Model highlights the successful integration of family-centred ICF-based clinical service delivery with a CBR strategy to provide equitable home-based early intervention and rehabilitation for CWDs and families in rural India.

The innovative EI model, with its globally-recognized clinical digital application, is being scaled-up in the state of Tamil Nadu and adopted across India in partnership with other NGOs

REFERENCES

Krishna D, Mutthukarrupan S, Bharathwaj A, Ponnusamy R, Srinivasan, S, et al. Rapid-cycle evaluation in an early Intervention program for children in South India: optimizing service providers' quality of work-life, family program engagement and school enrollment. Frontiers in Public Health. (2020).

Muthukaruppan S, Cameron C, Campbell Z, Krishna D, Srinivasan, S, et al.. Impact of a family-centred early intervention programme in South India on caregivers of children with developmental delays. Disability and Rehabilitation. (2020).

Hunt M, Ponnusamy R, Goulet A, Anthonypillai C, Krishna D. An integrated knowledge translation project to develop, implement, and evaluate a train-the-trainer program at a community rehabilitation program in Tamil Nadu, India. Disability and Rehabilitation. (2020).

Contact Information

franzina.research@gmail.com

https://earlyintervention.amarseva.org/