



Integrating the ICF, family-centred care and community-based rehabilitation in rural South India: The Enabling Inclusion model and app

Venkatachalaphy, N., Brien, M., Krishna, D., Coutinho, F., SR Srinivasan
Amar Seva Sangam, Ayikudy, Tamil Nadu, India

Background

- 2.21 % of population has disability.
- There are **30.38 million** Persons with Disabilities in India as per time adjusted figures of 2011 census.
- Prevalence of developmental delay and disabilities– 1.5 to 2.5 %
- From Birth to 18 years, there are about 7.8 million children with developmental delays and disabilities.
- **66%** Children With Disabilities have No Access to EI Therapy
- **72% of 5 year old children in India with disabilities** have never attended any educational institution
UNESCO's State of the Education Report for India 2019



Objectives

To develop an innovative evidence-based service delivery model for providing early intervention and rehabilitation services in LMICs with the following guiding principles:

- The **WHO's International Classification of Functioning, Disability and Health (ICF)** provides a framework to guide clinical practice for optimizing health, function, participation, and environmental and personal factors.
- The **family-centred approach (FCA)** recognizes the interrelated development of the child and family well-being.
- **Community-based rehabilitation (CBR)**, as a strategy, aims to enhance the quality of life for CWDs by meeting basic needs and facilitating participation and social inclusion.



Description

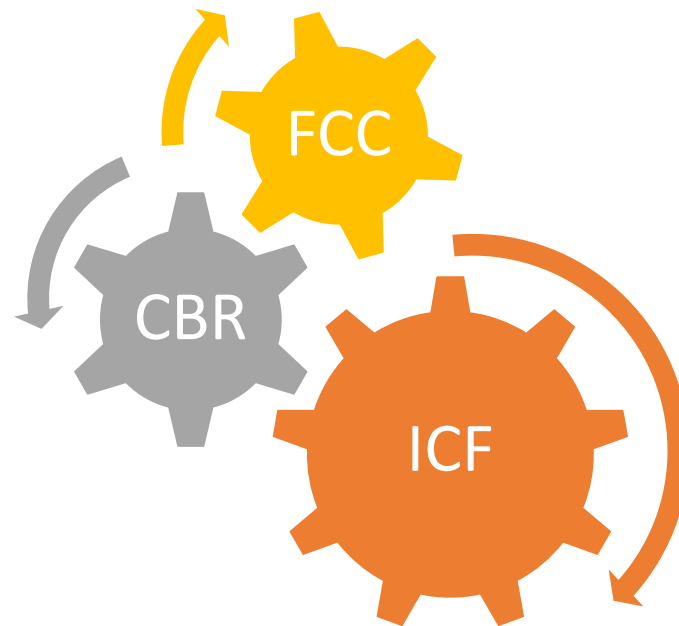
- In 2014, an innovative service delivery model, was developed and implemented by Amar Seva Sangam, an NGO in rural South India, to provide access to community-based early intervention services for CWDs.
- The model, named **Enabling Inclusion®**, is supported by a *digital health solution*, the **Enabling Inclusion® application**.
- It facilitates connectivity between families, community rehabilitation workers (CRWs), and rehabilitation specialists to provide evidence-based services in a low-resource context.



The Enabling Inclusion® Model: *The Integration of ICF-FCC-CBR*

A Global Health Solution to best support the needs CWDs and their families living in an LMIC setting.

Aims to maximize each child's potential for functional independence, participation, and inclusion.



Staff Structure and Human Resource Development

Block wise Approach

Team of Rehab Staff:

- Physiotherapist -1
- 1. Special educator -1
- 1. Speech trainers -1
- Community Rehab Workers – 4 or 5

Orientation Training:

CRW – One month

Rehab Professionals – 10 days

To develop knowledge, skills and attitude to work with children with disabilities using our model, approach and App



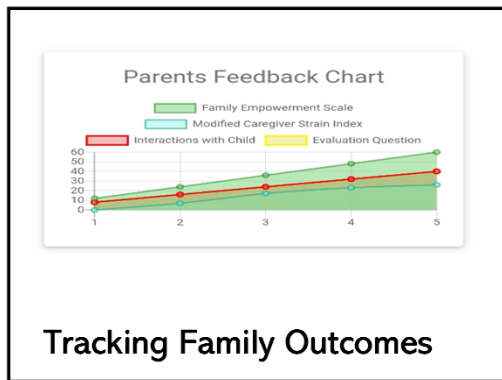
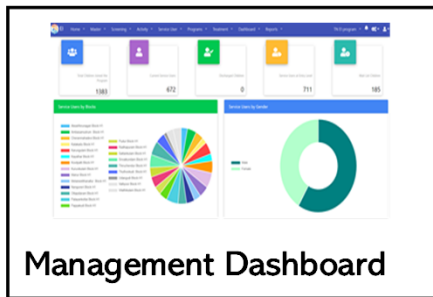
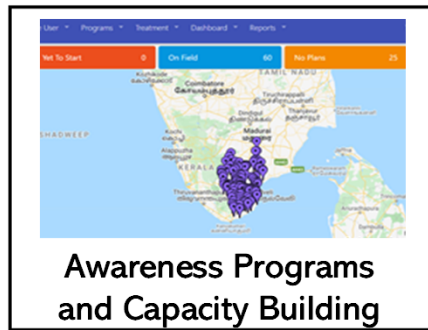


Enabling Inclusion® (EI) model

Supported by the EI® app



Digital Solution for Early Intervention and Child Rehab Programs



Screening Module



Assessment List(9)

Assessment Type	Status
Physiotherapy Assessment	Submitted
Vision Assessment	Submitted
Emotional Assessment	Submitted
Speech & Language Assessment	Submitted
Functional Assessment for Hearing	Submitted
General Assessment	Completed
Special Education Assessment	Submitted
Special Education Assessment	Submitted
Special Education Assessment	Submitted
Special Education Assessment	Submitted
Special Education Assessment	Submitted

General and Specialist Assessments & Child Outcome Evaluations

Goals

- Poor accessibility in school --> To facilitate suitable accessibility in school
- Negative attitude of school staff and poor acceptance on child with disability --> School staff understand right and needs of child with disability
- Peers do not cooperate with the child/bullying the child -->

Goal Setting and Intervention Plan

Calendar

Month	Day	Activity	Status
2020	December	Treatment - Special Assessment - CH2B -> Submitting Completion Measure	Completed
2020	December	Treatment - Special Assessment - CH2B -> Submitting Completion Measure	Completed
2020	December	Treatment - Special Assessment - CH2B -> Submitting Completion Measure	Completed

Daily Scheduling and Advance Tour Plan

Regular Therapy Visits and Support Services

The EI® Model's integrated modules

Validated screening tools

ICF-based Child and Family Assessment

Standardized evaluations across developmental domains and ICF components

Family-centred goal setting tool, parent-reported outcomes, and caregiver measures

Needs- and ICF-based intervention plan and activities

Family empowerment groups, capacity building, social media outreach, livelihood, assistive technology

Community disability awareness and inclusion groups (community, women, students)

Training child development workers, health workers, teachers, parent groups



1. Validated Screening Tools

- TDSC (Trivandrum Development Screening Chart)
- UNICEF/Washington Group CFM (Child Functioning Module)

2. ICF-Based General Assessment

Family-friendly questions addressing each ICF domain:

- Body Structure and Function
- Activities
- Participation
- Environmental factors
- Personal factors



3. Standardized evaluations across developmental domains and ICF components

GMFM (Gross Motor Function measure)

Wee-FIM (Pediatric Functional Independence Measure- Self-care, Mobility, Cognition)

Com-DEALL (Communication Developmental Checklist)

FACP (Functional Assessment Checklist for Programming)



4. Family-centred goal setting and caregiver measures

COPM (Canadian Occupational Performance Measure);
family priorities, goal identification, parental perceptions

FES (Family Empowerment Scale)

MCSI (Modified Caregiver Strain Index)

CI (Caregiver-child interaction measure)



5. Needs- and ICF-based Intervention Plan and Service Delivery



- Provision of **Assistive devices** to facilitate inclusion
- Home modifications
- Advocacy for access in public places
- **Medical and surgical camps**, consultations with specialists



6. Community-based Disability Awareness Program and Capacity Building

- Weekly awareness groups for women, community members, and school children in villages
- Training programs for local health workers, child development workers and school teachers
- Focus on knowledge provision, dispel stigma, change attitudes and practices to enable community and school inclusion



7. Family empowerment

- Family priorities & collaborative goal-setting
- Caregiver capacity building using a coaching approach
- Early Intervention parent support groups
- Group advocacy
- Parent social media groups for peer connection and mentorship
- Self-help groups for livelihood Initiatives



Significance

- The innovative EI model, with its *globally-recognized clinical digital application*, is now being used by 9 NGOs and in 4 states in India.
- Currently we are giving early intervention and child rehab services to 4140 children with disabilities in 3 districts of Tamil Nadu.
- Its use is being scaled up through global LMICs partnerships (Ethiopia).
- The EI Model highlights the successful integration of family-centred ICF-based clinical service delivery with a CBR strategy to provide *equitable and sustainable home-based early intervention and rehabilitation for CWDs and families* in rural India.
- The EI app has the potential to generate *large scale impacts to clinical practice in childhood disability in low-resource settings*.



Acknowledgements

We wish to thank *our funders* which have enabled us to develop the EI app:

Handi-Care Intl., Grand Challenges Canada, MIT Solve, Saving Brains, Azim Premji Philanthropic, World Vision, Bill and Melinda Gates Foundation, Vodafone, NexGen, United Way-Chennai, NASSCOM and the Tamil Nadu Government.

We thank *our research partners*: the University of Toronto, McGill University, the Harvard Centre on the Developing Child, and Kalasalingam Academy of Research and Education.

We also thank *our software developers*: Druvah IT Consulting.



Contact Information

Navamani Venkatachalapathy, PT
inclusionlead.coe@amarseva.org

Amar Seva Sangam-Enabling Inclusion
www.earlyintervention.amarseva.org

