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

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Background

- Globally, at least 10% of all children have disabilities. One of the most excluded and marginalized groups
- 80% of children with disabilities (CWDs) under age 5 years live in developing countries where access to early intervention services is unavailable or limited to urban centers.
- Challenges in low- and middle-income countries (LMICs) and barriers to inclusion include high disability stigma, lack of rehabilitation providers and services.







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



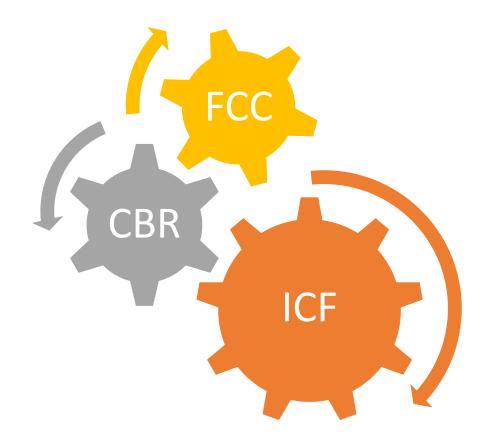
- In 2014, an innovative service delivery model, was developed and implemented by Amar Seva Sangam, an NGO in rural South India, to provide access to community-based early intervention services for CWDs.
- The model has been named **Enabling Inclusion**® and it is supported by a *digital* health solution, the **Enabling Inclusion**® **application** which 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.

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





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, peer support, 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



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





Rehab Specialists

Assess & Plan

Community Rehabilitation Workers – 1 x / week Rehab Specialists – 1 x / month

Therapy in Child's Home (Tele-rehab or In-person)





aws **EC2 Application Server**

Cloud Infrastructure provided by AWS

Screen

Request Request API Response Layer Response

Android Mobile App CRW, Therapist, Specialist

Existing Android tabs used by ASSA CRW team can be used for new mVBRI mobile application as well



Monitoring & Research

Reset treatment goals & plans

Evaluate 6 months



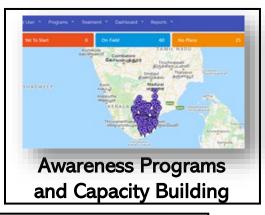


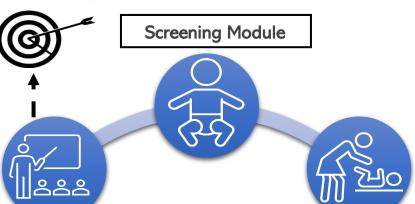


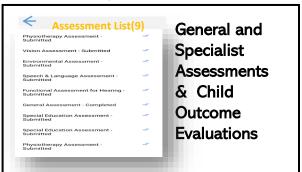




Digital Solution for Early Intervention and Child Rehab Programs







▼ 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.

Goals





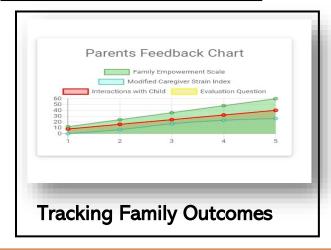




Peers do not cooperate with the child/hullvling the child -> CANCEL OK

Goal Setting and Intervention Plan

Poor accessibility in school -->





Regular Therapy Visits and Support Services





1. Validated Screening Tools

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

2. ICF-Based Child and Family 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



- Weekly visits by Community Rehabilitation Workers (CRWs) providing early intervention/ therapy to children in all domains of development, using a coaching approach with parents.
- Consultative joint visits of Rehab Specialists (PT/OT, speech trainer and special educator) with CRWs, using a train-the-trainer approach.
- Provision of Assistive devices and products to facilitate inclusion
- 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 goalsetting
- 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





- The innovative EI model, with its *globally-recognized clinical digital application*, is now being used by 5 NGOs, and in 4 states in India (Tamil Nadu, Assam, West Bengal, Uttar Pradesh) and has benefitted 3890 children and 8885 caregivers.
- Its use is being scaled up through global LMICs partnerships.
- 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 demonstrating the potential to generate large scale impacts to clinical practice in childhood disability in low-resource settings.

Significance



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