Discover Ability
AMAR SEVA SANGAM
Rehabilitation. Empowerment. Inclusion

# *Enabling Inclusion® Model and App*

Navamani V
Lead- Implementation and Capacity Building
Amar Seva Sangam, Ayikudy

10 January, 2025

# Introduction – Amar Seva Sangam

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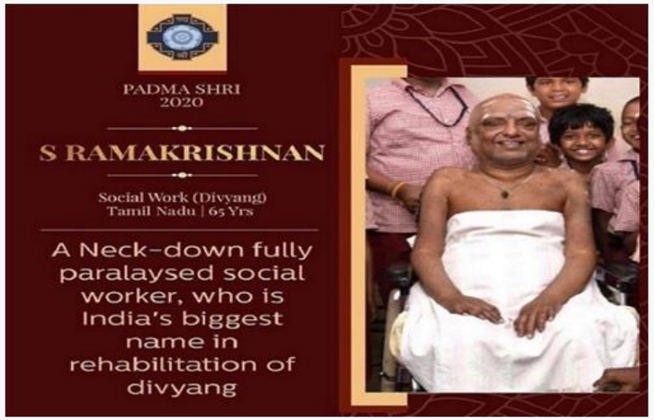
## Leadership




**Padma Shri* S Ramakrishnan (Founder President)**

Paralyzed from neck down (when he was a fourth year Engineering student), Mr.Ramakrishnan did not lose hope, but founded a centre to educate & rehabilitate poor rural disabled children.

**CA S. Sankara Raman (Hon. Secretary)**

A chartered accountant and a wheelchair user due to muscular dystrophy, heard about Amar Seva Sangam and joined Mr. S. Ramakrishnan in the year 1992.

We aspire to build a **Valley for the Disabled** and establish a Rehabilitation and Development Centre and developing models for self-help initiatives by integrating the disabled individuals with the society and improved living conditions.

**We build on the premise that disability is not a constraint but only a condition**

**We believe that disability is a matter of perception**

# *Developmental Disabilities -Status in India*

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## Incidence of Developmental Delay and Disability in India

- 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.

## Current Sales Trends:

- 66% of 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

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

- 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.
- 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.

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# *Out Solution is*

Enabling Inclusion Model

Enabling Inclusion App

# *Enabling Inclusion Model*

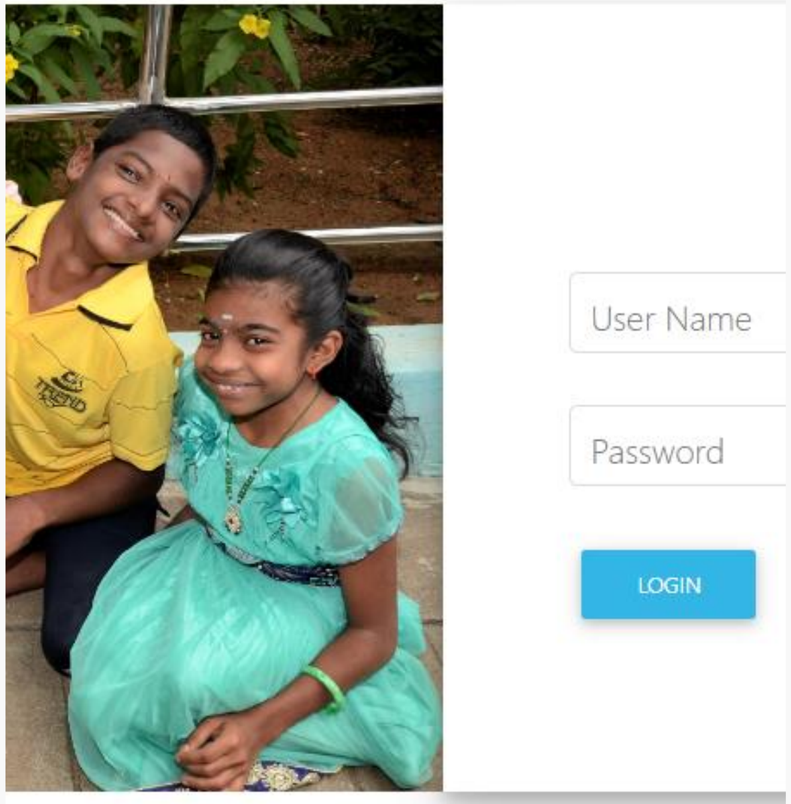
**CBR Program**

- Community Based Rehab Model leveraging and strengthening local resources and services

**Features**

- Staff structure- Block wise geographical teams
- Training - Induction and on the job
- Therapy visits - weekly
- Community, School and Women's Awareness
- Parents training and empowerment
- Screening
- Medical camps
- Assistive Technology
- Referral and linkages
- Collaboration and partnership

# *Enabling Inclusion App*

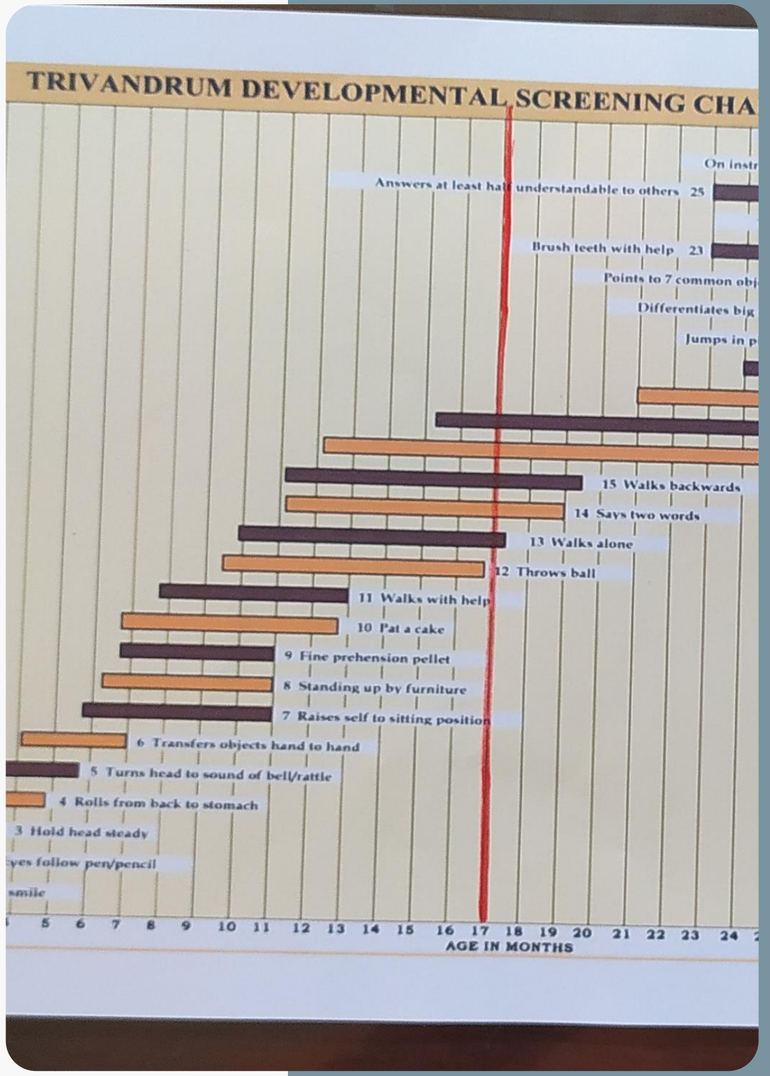



**Documentation and Monitoring**

- Web and Mobile app
- Cloud server
- Therapy visits monitoring
- Staff activity monitoring
- Program Monitoring
- Children/Service users Monitoring

# *Developmental Screening*

- Tools used- Trivandrum Development Screening Chart and UNICEF Washington Child Screening tool
- Program summary - Location, Date and Time, How many children screened and identified with Developmental delay
- Demographic data and screening details
- Opportunity to convert children screened positive into service user



# *Assessment Module*

- Parents/Caregivers Consent
- Demographic Data
- Initial assessment – follows WHO’s ICF Model
- Various professional assessment (PT, OT, Speech, medical, psychology, vocational, AT, etc.)
- Environmental assessment

# *Goal Setting*

- Involving Parents and caregivers for goal setting.
- Using Canadian Occupational Performance Measure
- Functional Goal setting

# Process Flow

## ICF Framework for Assessment and Intervention

Community Workers

Screen

Rehab Specialists

Assess & Plan

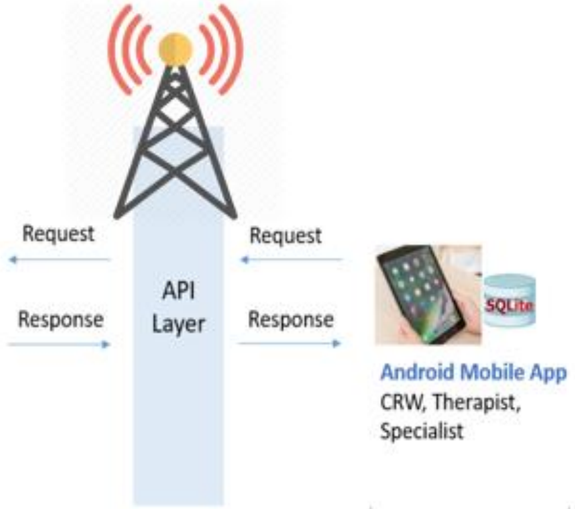
Family Centered Services
Community Workers and Parents Supported by Rehab Specialists

Therapy in Child's Home
Nearby Centre or Mobile Clinic

Monitoring & Research

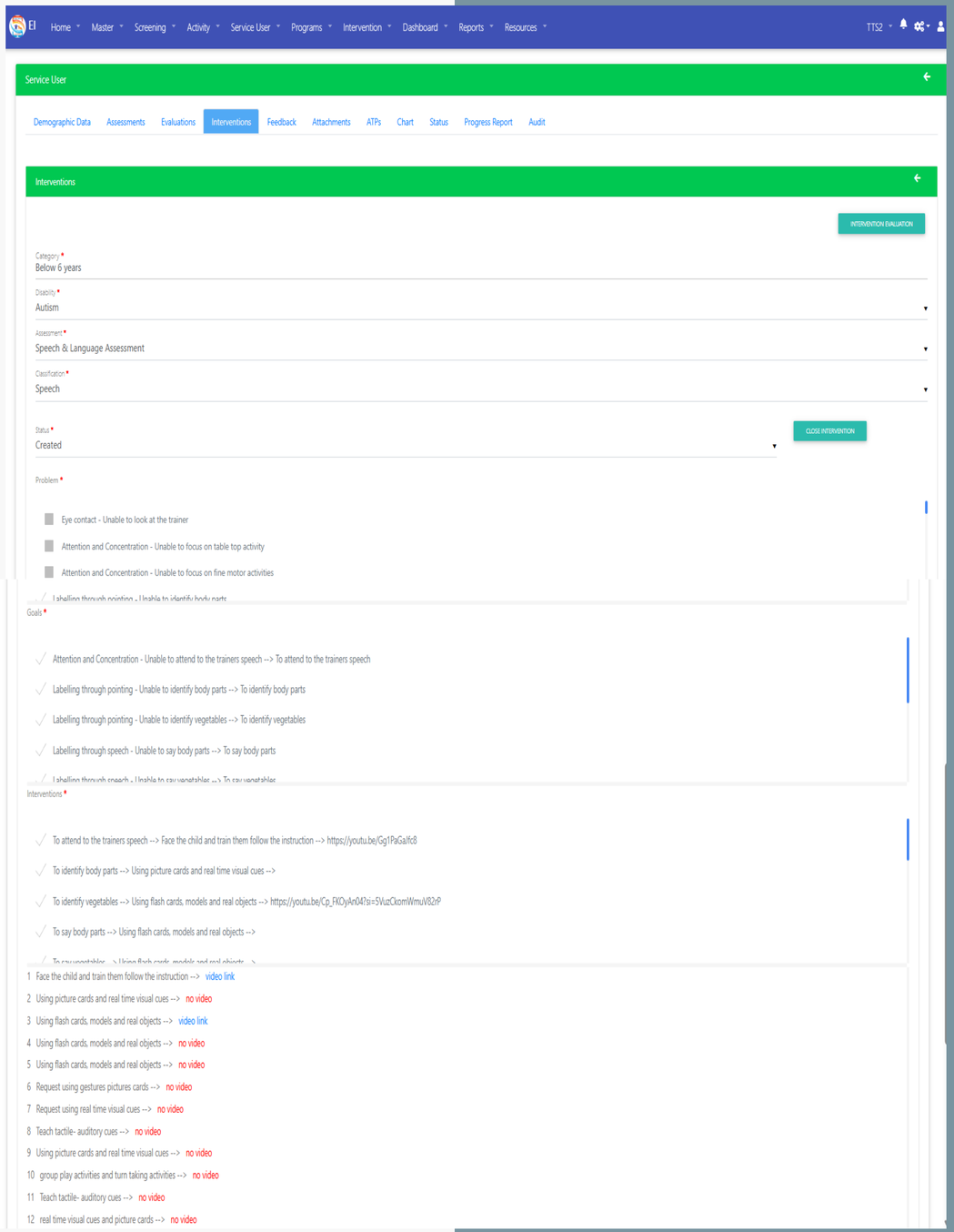
Reset intervention goals & plans

Evaluate 6 months



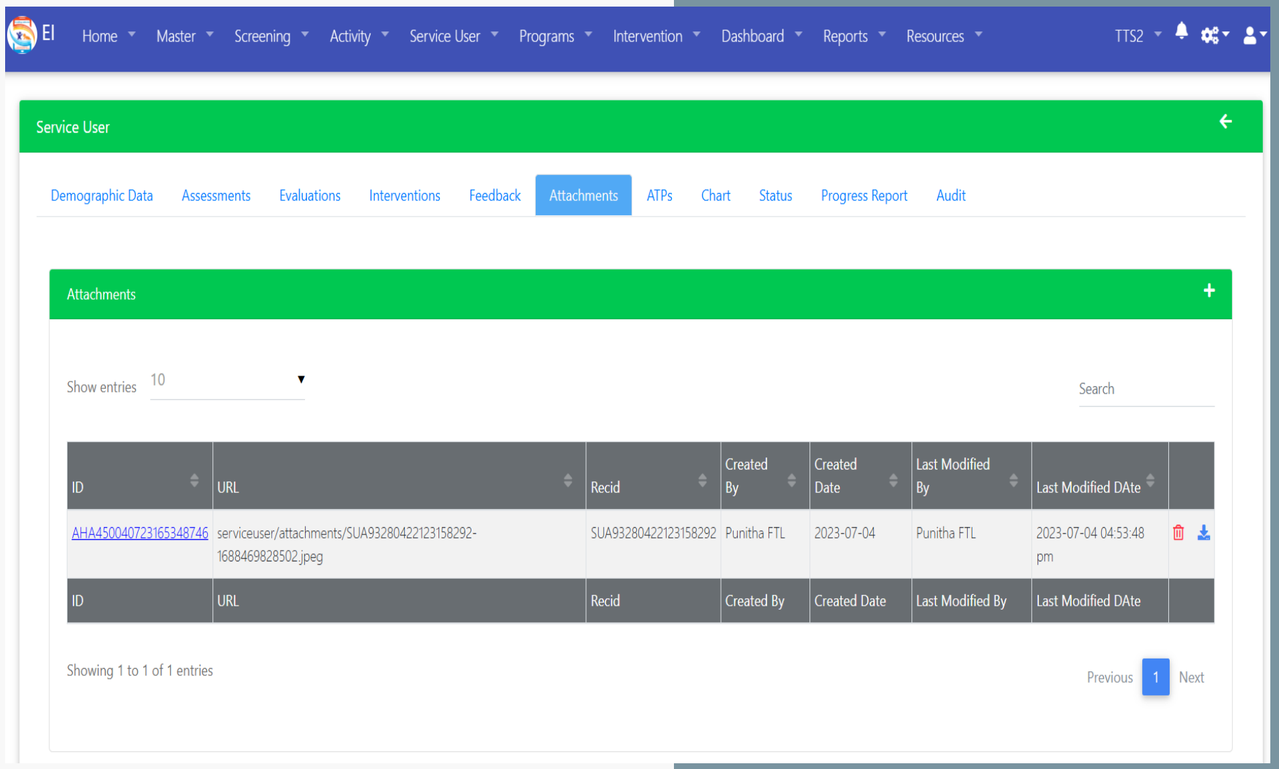
# *Intervention Module*

- Intervention plans based on validated drop-down options
- Based on the selected goals, intervention plan are chosen by the rehab team
- Custom intervention if required
- Can be given as printout for parents/caregivers (or accessed via parent login)
- Videos for certain intervention



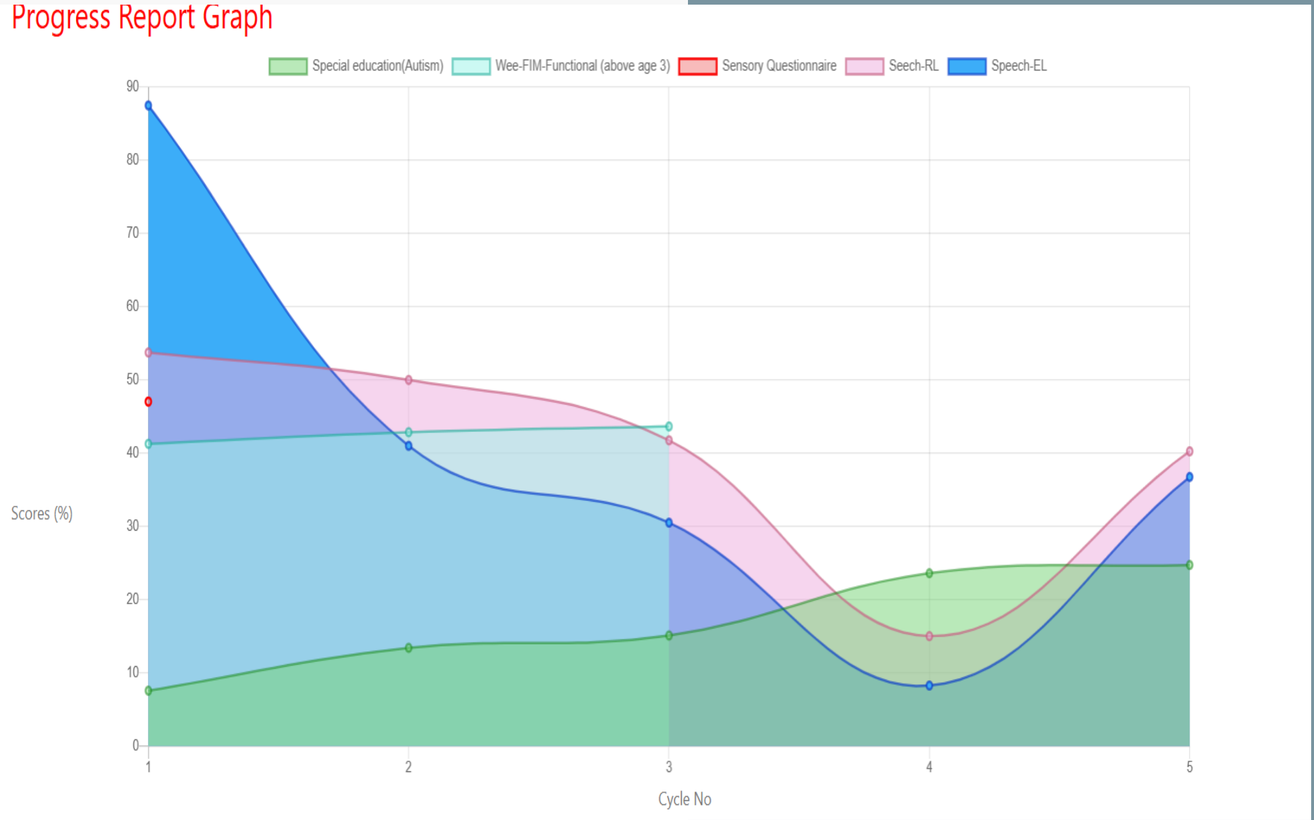
# *Attachment Section*

- Medical reports
- Assessment from other service providers
- UDID and other required documents can be attached and retrieved at our convenience



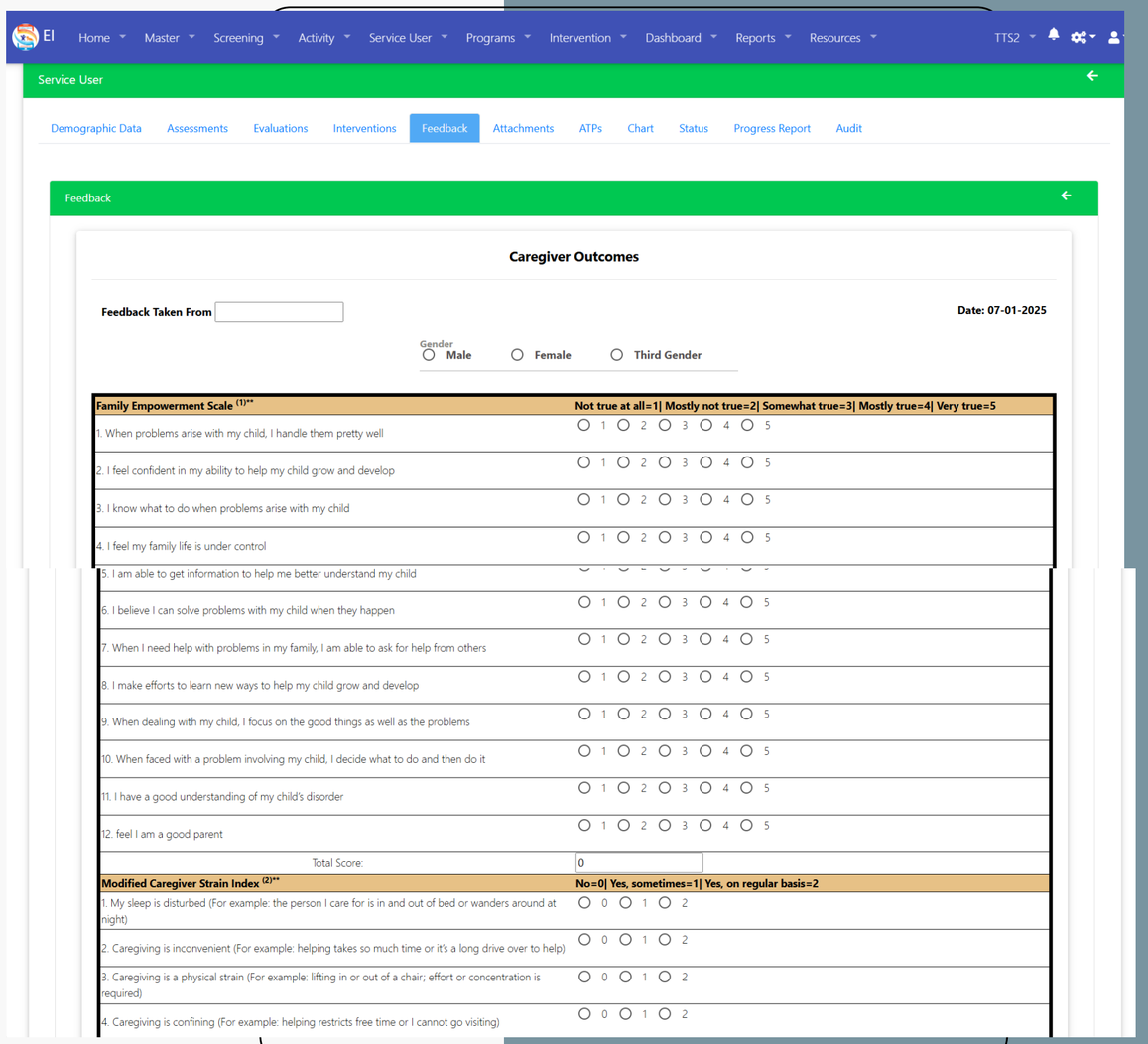
# *Outcome measurement*

- Outcome tools for various domains in app - Standardized tools (from NIEPID and other institutions) and ASSA developed tools.
- Periodical evaluation of children to evaluate progress and reset intervention pklans
- Graphical representation of scores



# *Feedback by caregiver*

- Caregiver feedback module included
- Periodical feedback taken on caregivers strain and empowerement, communication and engagement with the child and general satisfaction about the services.



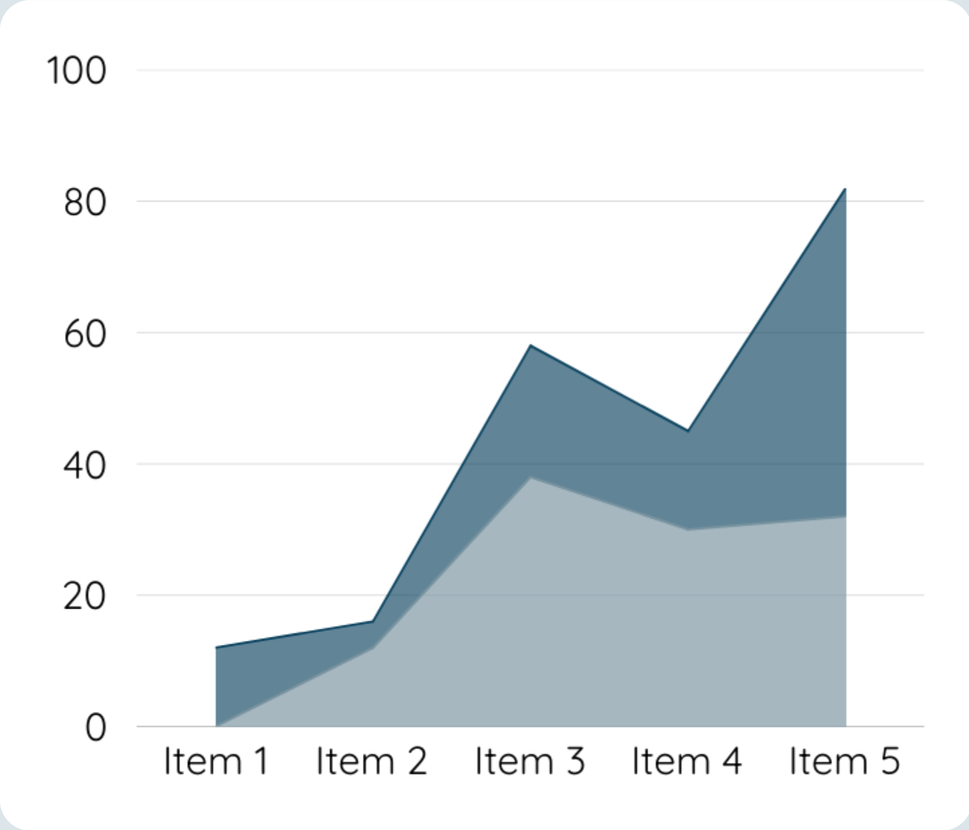
# *Dashboard -Program Output in a glance*

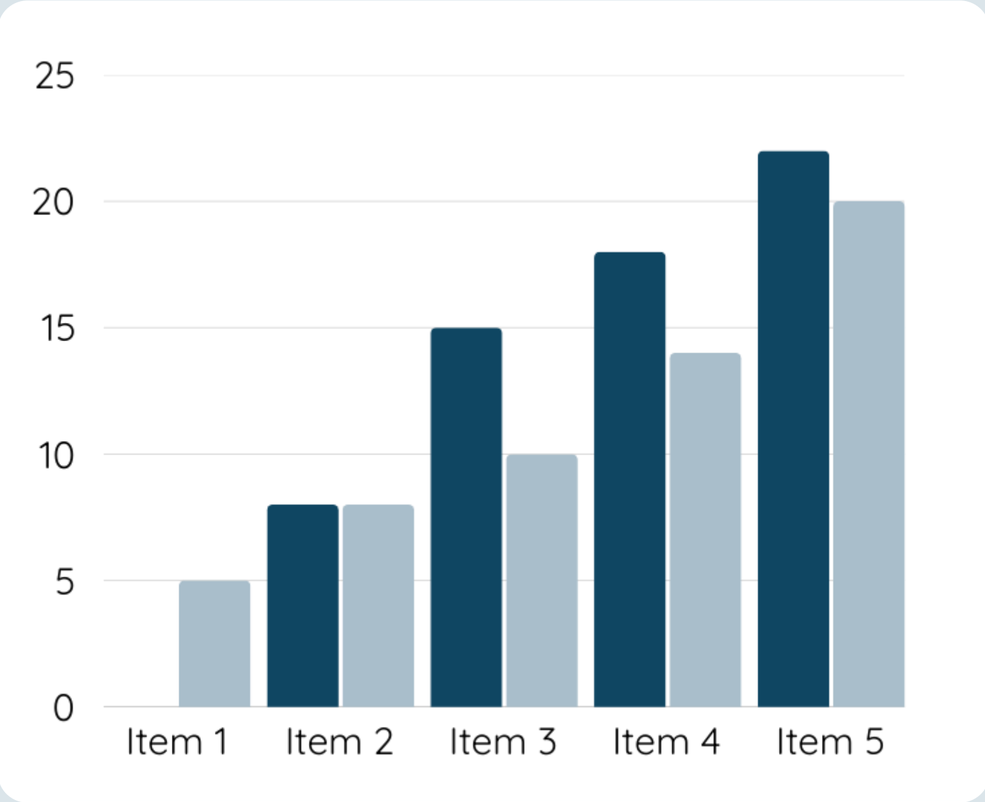
Service user - Age, Gender, Disability wise, Location wise

Therapy visits - Daily and monthly target and achievements

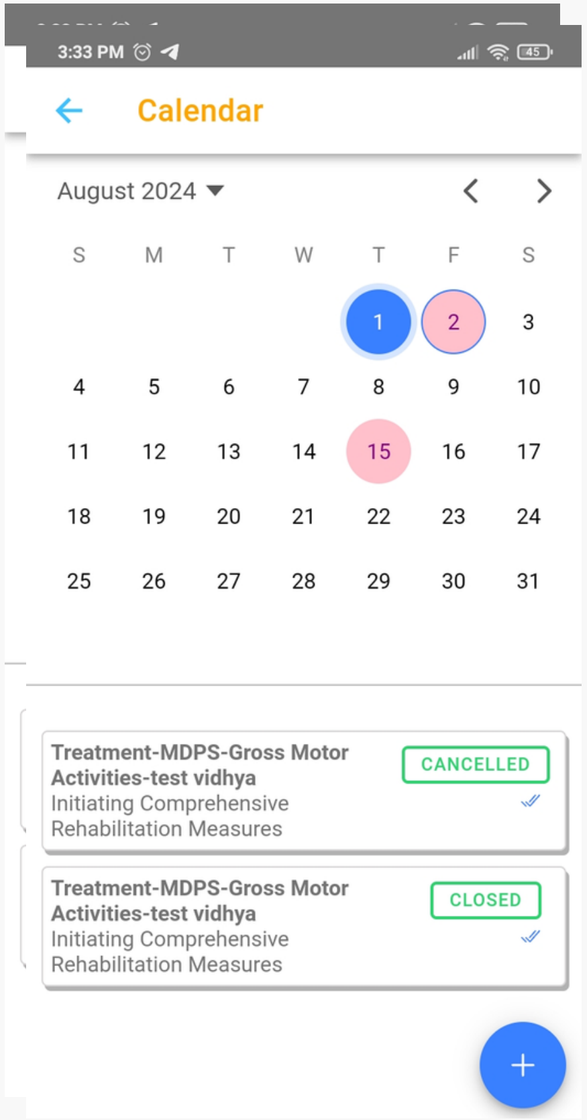
Staff and service user ratio block wise

School admission and any other program outputs and outcomes

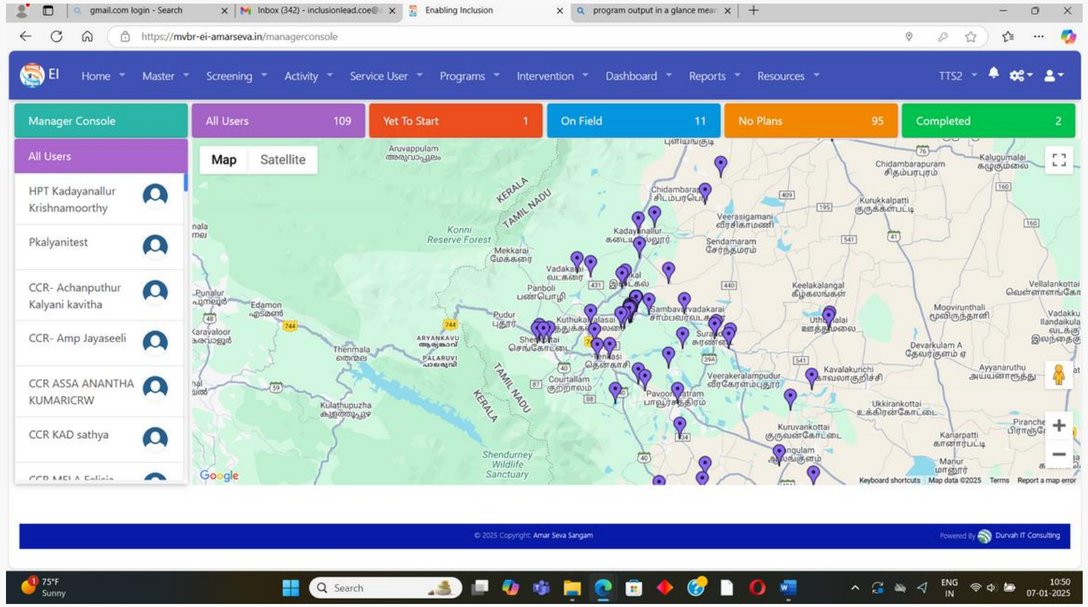


# *Staff Monitoring*

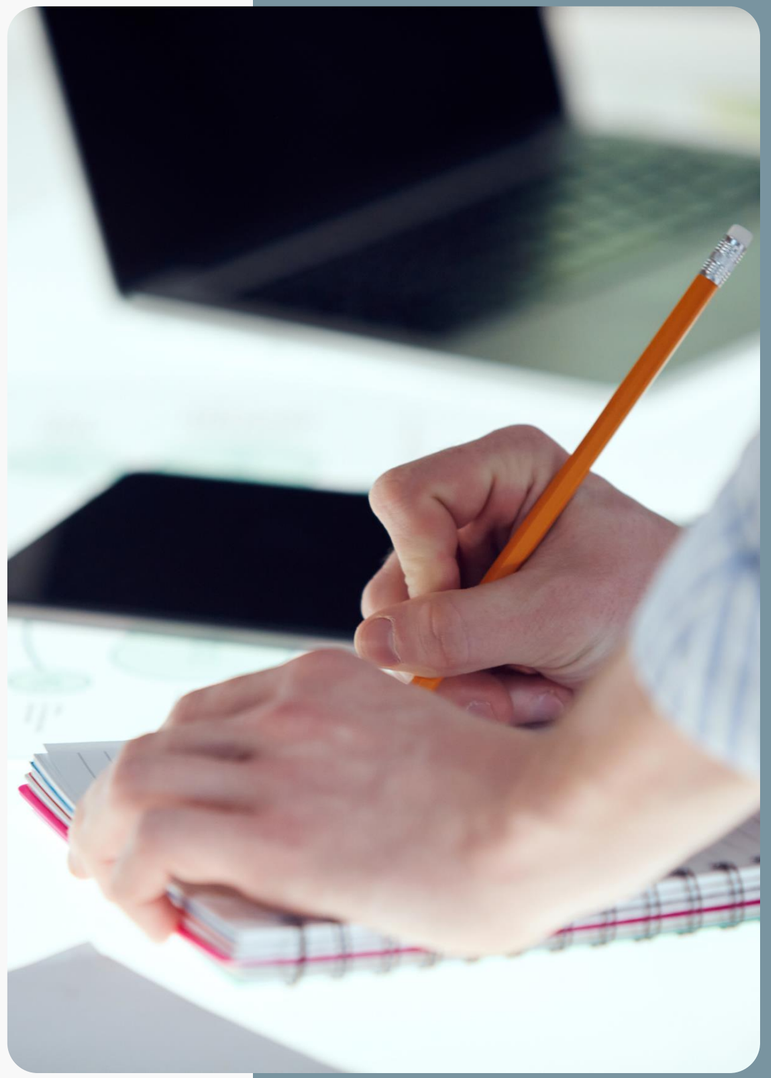



- Monthly and Daily Work Plan in calendar
- Attendance monitoring
- Check in and check out for each work completion with location and duration through GPS location technology



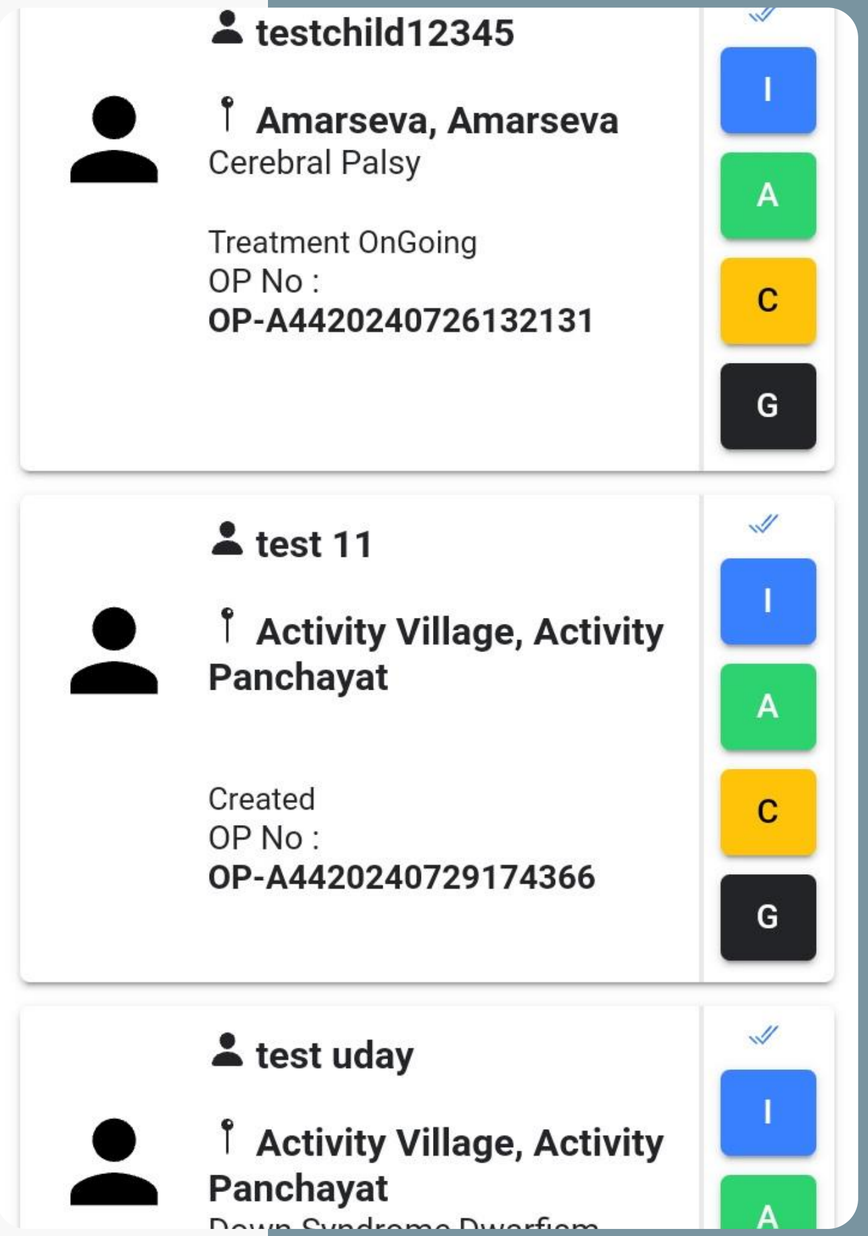
# *Programs and Events*

- Awareness Program
- Training Program
- Medical camps and any other special programs
- Documented with location, participant details, test results if any and duration

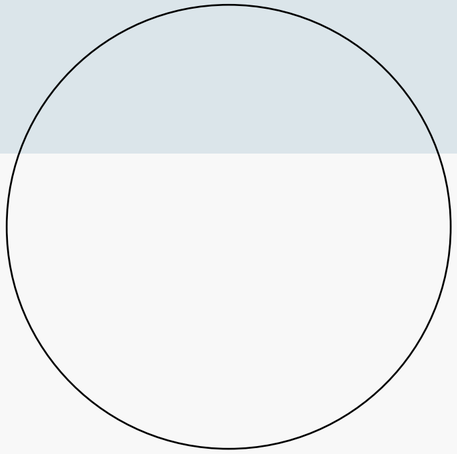


# *Therapy Visits Planning*

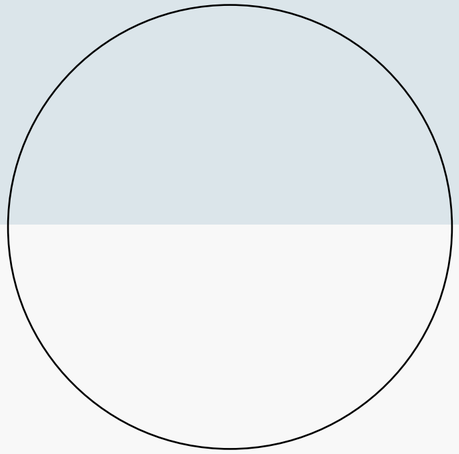
- No of visits required the child required, staff attending the child can be planned
- Date wise planning
- Taken as targets and goes in to staff calendar



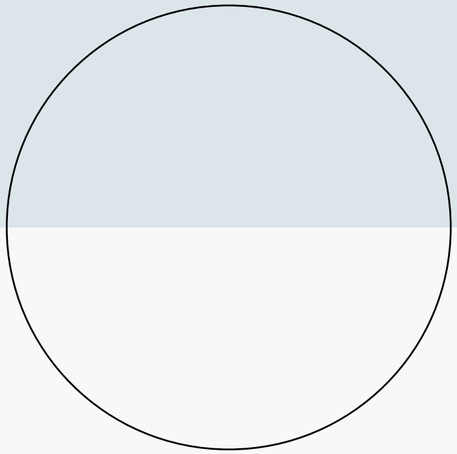
# *Parents Login*



Child assessment and goals

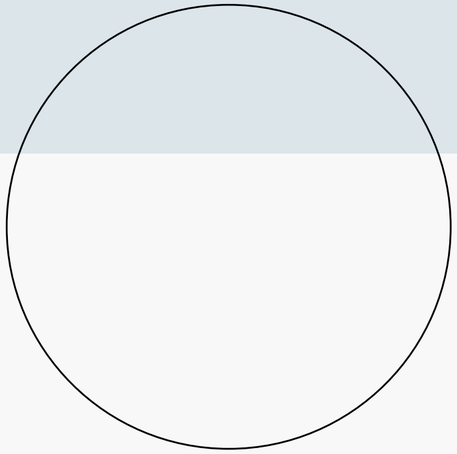


Therapy plans and videos

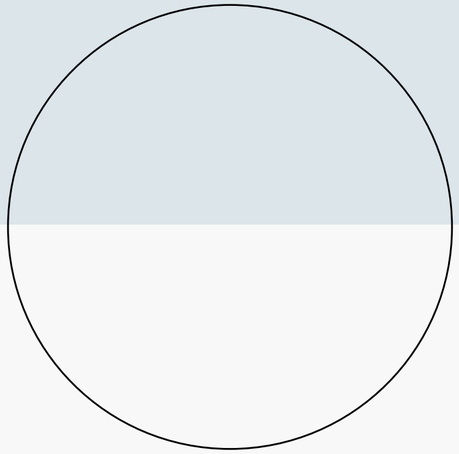


Progress reports

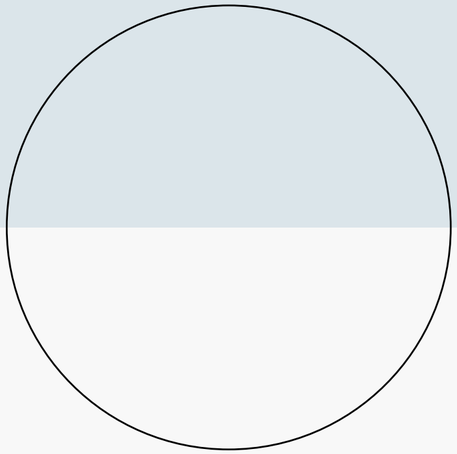
# *Parents Login*



Calendar for therapy schedule



SMS reminders of appointments

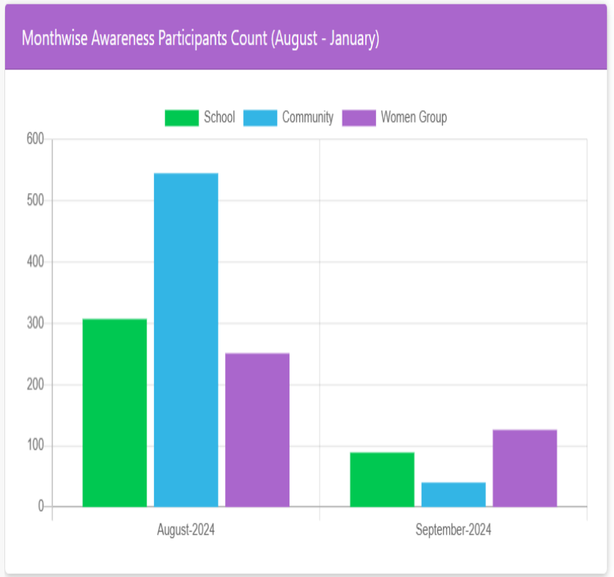


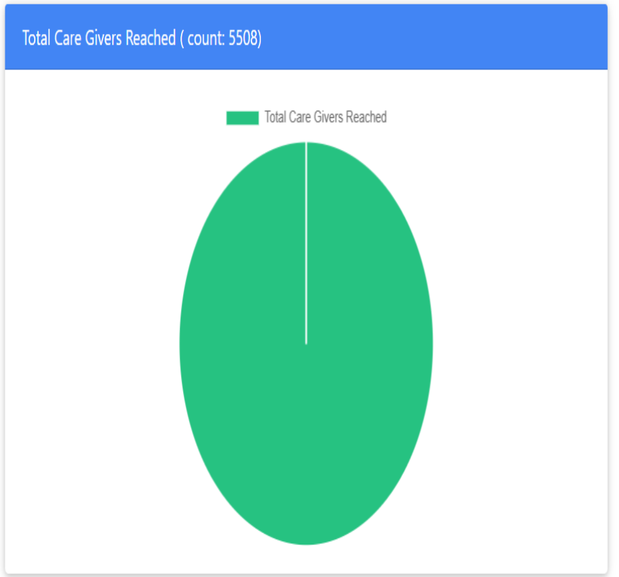
Parents provide scoring and feedback on therapy sessions

# *Reports*

- Reports on various parameters used in the program can be taken
- Can be customized to various management and donor needs. For ex: how many caregivers trained, progress of children, number of goals achieved, number of therapy visits completed, etc
- Daily, Weekly, Monthly, Quarterly reports can be taken
- Real time data
- Login and View permission

| Disability | Count |
|---|---|
| ADHD | 104 |
| Autism | 273 |
| Blindness | 5 |
| Cerebral Palsy | 480 |
| Cerebral Palsy- GMFCS Level I | 16 |
| Cerebral Palsy- GMFCS Level II | 20 |
| Cerebral Palsy- GMFCS Level III | 27 |
| Cerebral Palsy- GMFCS Level IV | 28 |
| Cerebral Palsy- GMFCS Level V | 21 |
| Cerebral Palsy with Intellectual Disability | 63 |



# *Research*

- Appropriate data can be collected
- Real time data
- Support research activities
- Give perspectives for future research and intervention areas - For ex: Location and type of disability, Caregiver economic status and engagement level
- All aspects of Program documentation

frontiers | Frontiers in Public Health

Sections Articles Research Topics Editorial board About journal

Rapid-Cycle Evaluation in an Early Intervention Program for Children With Developmental Disabilities in South India: Optimizing Service Providers' Quality of Work-Life, Family Program Engagement, and School Enrollment

Dinesh Krishna[1,2,3*] Sankar Sahayraj Muthukaruppan[1] Aravind Bharathwaj[1]
Ramasubramanian Ponnusamy[1] Bala Murugan Poomariappan[1] Sathiya Mariappan[1]
Ayesha Beevi[1] Janna MacLachlan[2,3] Zoé Campbell[3]
Chamila Anthonypillai[3] Marie Brien[1,3] Cathy Cameron[2] Marina Flatman[3]
Lesley Perlman[3] Stephanie Seilman[2,3] Abhinavaa Jevapragash[2,3]

ELSEVIER

Research in Developmental Disabilities

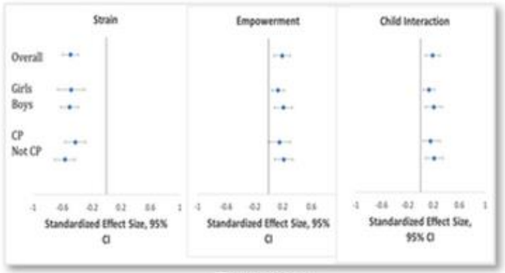
Volume 154, November 2024, 104829

Motor development trajectories of children with cerebral palsy in a community-based early intervention program in rural South India

Marie Brien [a b 1 2] ✉, Dinesh Krishna [a b 2 3 4] ✉, Ramasubramanian Ponnusamy [a b 2 5] ✉, Cathy Cameron [b 6 7] ✉, Rahim Moineddin [c 6 8] ✉, Franzina Coutinho [a b d 2 9 10] ✉

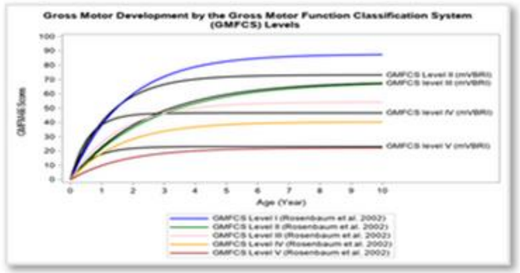
# *Partnership*

## Proven Outcomes




**Parents:**

- Decreased Strain
- Increased Empowerment
- Improved Child Interaction




Improved Child Development

NEWS TODAY
11/02/2020
Page # 03

**'School enrollment rate of special children up'**

*Early intervention therapy helps them, says study*

*Guv to inaugurate Amar Seva Sangam's conference 14 Feb*

[NT Bureau]
Chennai, Feb 11:

The school enrollment rate of children with special needs increased from 69 per cent to 85 per cent when they received early intervention therapy, finds a study by Amar Seva Sangam, Arckadi (ASSA), a private non-profit organisation, in the field of disability management.

According to a press release, the study was conducted in association with the University of Toronto and McGill University, Canada on the initiative of ASSA's Village-based Early Intervention & Rehabilitation Programme that covered 1,332 children with special needs.

ASSA's study found that the severity of disability and the lack of early intervention were the two primary reasons that prevent the children with special needs from attending schools. The latest enrollment was seen with children with cerebral palsy (CP), particularly those with more motor severity and cognitive impairment. Children with higher early intervention programme attendance levels had higher rates of achieving school enrollment, the release said.

In order to share its experiences in early intervention, and to highlight other successful early intervention models and interventions from across the world, ASSA is organising an international conference on 'Early intervention for children with special needs' in Chennai. The two-day conference will be inaugurated by Governor Banwarilal Purohit 14 February.

There will also be two pre-conference workshops 13 February on the topics - 1) Designing, implementing, monitoring and scaling-up early intervention programs for children with disabilities, and 2) Home-based early intervention for children with developmental disabilities and cerebral palsy: A family-centred interdisciplinary approach.

The international conference will have presentations from more than 30 experts on a wide range of themes such as early identification, early stimulation, intervention through play, assistive and adaptive technology, inclusive education, and social security schemes, among others.

About 300 participants, including the executives of non-governmental organisations, physiotherapists, occupational therapists, special educators, paediatricians, doctors and senior government officials from different parts of the country and the world are expected to attend the workshops and the international conference, the release said.

4 x the impact

If programs are currently supporting 50 children, with EI app and model you can support 200 (with the same implementation cost).

75%
Decreased Caregiver Strain and increased parent empowerement

Regular support and therapy services reduced caregiver strain / stress / burden

60 → 95%
Programme Engagement

High level of family engagement improved child development in all domains.

<30% → 85%
School Enrollment Increase

Rehabilitation services improved school enrollment and integration.

Center on the Developing Child
HARVARD UNIVERSITY

McGill UNIVERSITY

UNIVERSITY OF TORONTO


Krishna D, Sankara Raman Srinivasan SR. 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. 30 November 2020 https://doi.org/10.3389/fpubh.2020.567907

Muthukaruppan SS, Srinivasan SR, et al. Impact of a family-centred early intervention programme in South India on caregivers of children with developmental delays. Disability and Rehabilitation. Received 28 Aug 2019, Accepted 08 Oct 2020, Published online: 25 Oct 2020. https://doi.org/10.1080/09638288.2020.1836046

# *Awards and Recognitions*

**2023 Zero Project Award for Independent Living** presented at United Nations (Vienna, Austria)

**The Spindle's 2020 Most Inspiring Digital Innovation** (Netherlands)

**2020 Project Management Institute Award** (India)

**2020 Zero Project Inclusive Education Award** (Vienna, Austria)

**2019 World Cerebral Palsy Day Major Award: Medical/Therapeutic** (Australia)

**2019 MIT Solve Award for Early Childhood Development** (New York, USA)

**2019 Microsoft Equal Opportunities Award** (India)

**2016 Vodafone Mobile for Good Award** (India)

**2022 ATF Award for Best Assistive Technology Initiative for NGOs** (India)

feathers
Refresher Training on
Community Bas
Early Intervent
17-19, September 2024

*Thank you*