

A Family-Centered Pediatric Assistive Technology Provision Program in Rural South India

Marie Brien PT, MSc

Associate Director of Research and Capacity Building

Amar Seva Sangam, Ayikudi, Tamil Nadu

February 17, 2023

Background of our organization and project



- Amar Seva Sangam (ASSA) is an NGO started in 1981 in rural South Tamil Nadu, India, providing services to children and adults with disabilities.
- ASSA's Enabling Inclusion® Program provides early intervention and rehabilitation services for children with disabilities.
- The Pediatric AT Provision Program was launched in October 2020 to provide needed pediatric assistive products by responding to local barriers to AT access with specific solutions.



Objectives of the Program

Function and Participation:

- Enabling a rights-based AT access for equal opportunities for all ages.
- Pediatric AT provision maximizes child development and functional independence.

Accessibility and Inclusion:

- Access to education and school participation with peers
- Maximizes involvement in community life

Innovative aspects of the Pediatric AT Provision Program

- Identifies local AT barriers and facilitators using an organizational/regional level survey based on:
 - WHO's Priority Assistive Products List (APL)
 - Principles of AT access (5As & Q principles)
- Responds to local barriers to AT access in low-resource rural India with specific solutions identified by stakeholders.
- •Catalyses AT access by supporting various stakeholder groups:
 - Supports children with disabilities with out-reach
 AT service provision.
 - Supports families by facilitating local AT camps & co-funding for APs.
 - Supports rural rehab specialists with capacity building, a comprehensive AT service provision framework, and the procurement process.
 - Supports local AT suppliers with training and expertise.

The Essence of our Pediatric AT Program

 Based on locally identified barriers and facilitators, according to the WHO's principles of AT access:

Accessibility, Adaptability, Acceptability, Affordability, Availability & Quality

- Capacity-building of rehab service providers on assessment, prescription, order, fit/adaptation, training, use of AP.
- Implementation of decentralized AT assessment camps and AP service provision in rural South Tamil Nadu
- Identification of local suppliers for provision, adaptation, repairs of APs.
- Shared-cost structure according to socio-economic assessment, AT fundraising campaign by Handi-Care Intl. (Canada)
- Community awareness programs and parent groups to address AP-related stigma
- Provision of educational programs for service-users and families





The Impact created since 2020

- 102 rehabilitation workers trained in AP assessment, prescription, order, fit/adaptations, training and follow-up.
- 2 therapists trained as AT coordinators to guide, monitor and evaluate the practice.
- 30 out-reach AT camps held since 2020 in 3 southern of state of Tamil Nadu- Tenkasi, Tirunelveli, Thoothukudi Districts (pop. of 6.3 million people).
- A total of 1711 APs distributed to children with disabilities.
- AT Guidebook for local Rehab workers developed
- Parent groups, community awareness groups throughout the districts.

Assistive Products Distributed since 2020

Type of Assistive Products (AP)

Hearing Aid and other accessories

Wheelchair (power and manual)

Mobility Devices - Walker/ Rollator

Postural Devices (CP chair, Corner chair, Standing Frames)

Adaptations (to AT or environmental adaptations

Orthotics - AFO / KAFO / Other

Total #

of AP Distributed

53			
18			
72			
188			
585			
989			
1711			

A Functional Independence and Participation Story



- Sathiyamoorthi, 12 year-old boy with spastic cerebral palsy
- Able to ambulate with a rollator walker for short distances with much effort and energy expenditure due to severe tightness in legs.
- Received a new manual wheelchair which he propels efficiently for long distances.
- Able to participate in an inclusive school and community activities with peers.

Financing, Sustainability, Challenges

• Financing:

- Co-payment model by family based on socio-economic assessment.
- Major funder- Handi-Care International, Canada.
- Various sources of funding; national and internal donors, government.

Sustainability

- Expansion of ASSA's Enabling Inclusion® Program with 9 licensed partner NGOs through India, and globally.
- Scaling of program with state of Tamil Nadu's Dept of Health, Disability Dept and Education Dept.

Challenges:

- Creating enabling environments: physical and social barriers (stigma).
- Team coordination for all aspects of AT provision with distant service areas.

Next steps for the Pediatric AT Provision Program



- Implementation of the 'Pediatric AT Provision Module', developed for the EI® app, providing rehab workers with a step-by-step roadmap to AT service provision for each child receiving services.
- Scaling of our model to other organizations in various LMIC and low-resource contexts in India and globally.
- Expand the range, quality, and availability of pediatric mobility aids for a cost-effective supply.
- Train local and regional vendors for supply/distribution & servicing of custom postural support devices using sustainable materials.

