

# A Life of Dignity For All

## The Journey of Shishu Sarothi

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Persons with disabilities (PwDs) account for 15 percent of the total world population, of which 80 percent live in developing countries. According to Census 2011, 2.21 percent are living with one or more form of disabilities in India. This group of people remains the most marginalized and vulnerable in society. The reasons are inaccessible environment, discriminatory practices and non-inclusion in society.

Shishu Sarothi Centre for Training & Rehabilitation of Persons with Multiple Disability located in Guwahati has been working with children and persons with disabilities since 1987. Starting modestly with two children in a one-room setting, in its early days, the organisation was a centre primarily addressing the needs of children with Cerebral Palsy (CP). However, over the last three decades, it has grown into a leading regional level institution, working to enable and empower children and persons with disabilities for their full and effective participation in an inclusive society that respects their inherent dignity and autonomy.

The vision is to create an inclusive world where PwDs – children, women and men – live on equal terms with respect and dignity, enjoy their rights and fundamental freedoms and are valued as a part of human diversity and humanity. A dedicated team of professionals works towards the realisation of this vision by upholding and advocating the rights of children and persons with disabilities, ensuring equal opportunities, promoting their inclusion and full participation in a non-discriminating, barrier-free society.

The uniqueness and sustainability of our model lies in the multi-faceted work ranging from early intervention for very young children to special education provided for children and young adults with disabilities between the ages of three and eighteen. There are also services provided to children with different disabilities, such as intellectual disability, deaf-blindness and multi-sensory impairment and children and young adults with high-support needs through a rights-based framework. We work through the twin-track

approach of service delivery as well as rights-based advocacy. The major thematic areas include education, health, advocacy and research.

### **Inclusive Education**

In order to align the need of education for children with disabilities with the Right to Free and Compulsory Education Act (RTE) 2009, as well as the Rights of Persons with Disabilities Act (RPWD) 2016, our work in the area of education involves the promotion of inclusive education through several centres and units which include the following.

#### *Centre for Inclusive and Vocational Education (CIVE)*

This unit provides all-round educational and therapeutic inputs for children with developmental disabilities, including a Reverse Inclusion Playgroup, an equipped Information and Communication Technology (ICT) Lab, a school readiness programme for children with autism spectrum disorder and other Pervasive Developmental Disorders. At the centre, a diverse team of special educators, therapists, counsellors and social workers work together to achieve the goal of Inclusive Education. There are several units under the Centre for Inclusive and Vocational Education (CIVE).

*Playgroup Unit* is a *Reverse Inclusive Class* in which both children with and without disabilities learn together. The main emphasis on learning is given through developmentally-appropriate and child-centred methods which provide opportunities for all-round development.

*Functional Academic Unit* focuses on developing functional literacy and numeracy skills to support children in carrying out their daily living activities smoothly and lead an independent life with minimum support.

*Functional Unit* focuses on developing prevocational skills, life skills and also work-related behaviour so that students can make a smooth transition towards vocational training.

*Special Teaching Unit* caters to children with High Support Needs in the younger age group to create awareness of self and environment and

development of perceptual skills through multi-sensory approaches.

*Leisure Learning Unit* comprises children who, again, have High Support Needs and require greater support. The students in this unit need extensive support across all domains of development and are helped to develop basic skills for everyday living in order for them to lead life with dignity, self-respect self-confidence and acceptance.

*Vocational Unit* trains young adults with disability in various vocational courses to empower and equip them with skills for employability in the long run.

Physical Rehabilitation Unit provides therapeutic services. Students avail of physiotherapy and speech therapy from trained professionals for a minimum of two days in a week to achieve physical and developmental milestones on a need-based approach through short- and long-term goals.

*ICT Lab* (Information, Communication and Technology) has at its core the objective of assisting persons with disability to become computer literate. Special assistive devices and software according to individual needs assist students in learning basic computer skills.

The organisation has adopted a multi-faceted approach towards the promotion of inclusive education. Reverse Inclusion was initiated in 2016. A typical preschool curriculum is followed in which Special Educators and Montessori-trained teachers collaborate to ensure that all children are learning to the best of their abilities. The organic manner in which children with and without disabilities interact with one another is a delight to see.

Over the years, many children have been mainstreamed to regular schools. Teachers from *Shishu Sarothi* continue to support teachers in these schools and follow-up on the progress made by the children. Pre-enrolment sensitisation and orientation programmes for mainstream schools are organised for regular schools embarking upon the journey towards inclusion.

In September 2018, the Government of Assam and the National AYUSH Mission under the Ministry of Health and Family Welfare launched the Jivadhara Scheme, a pilot scheme aimed at introducing yoga for children with disabilities in the district of Kamrup, Assam, in association with *Shishu Sarothi*. This new initiative has been very effective as it complements other therapies already underway at the Centre and uses techniques of chanting, *pranayama* (breathing exercises), warm

up exercises, and *asanas* along with child-friendly activities to promote mindfulness. The yoga sessions are held for an hour each week. There are regular meetings which are conducted with parents to introduce them to the idea of yoga and its benefits for children with disabilities. Interestingly, most parents attend these yoga sessions along with their children.

*RAISE-NE (Regional Action on Inclusive Education in the North East)*

The RAISE-NE (Regional Action on Inclusive Education in the North East) project was initiated in 2016 to complement the programme of *Sarva Siksha Abhiyan (SSA)* on inclusive education to improve the quality of education for children with disabilities in government/government-aided schools in selected districts of Assam, Manipur, Meghalaya, Nagaland and Tripura. *Shishu Sarothi* is currently working with five SSA schools in the district of Kamrup (Metropolitan) and is set to expand services in another district. The main goal of the programme is to promote and advocate quality inclusive education through capacity building, sensitisation, training of teachers on curriculum adaptation, universal design for learning and alternative assessment methodologies.

*Sparsh Unit*

This unit provides comprehensive need-based services to persons with deaf-blindness (Db), a unique disability which is a combination of visual and hearing impairment and Multi-Sensory Impairment (MSI) that occurs in people between the age of 0 and 40 years. The programme was initiated in 2015 in two districts of Assam, focusing mostly on rural areas with support from Sense International India and provides home-based services which include counselling, educational facilities with parent-training and distribution of assistive devices, such as hearing aids and Braille kits.

*Human Resource Development Department*

This HRD conducts Rehabilitation Council of India (RCI)-approved training programmes to create a cadre of trained rehabilitation professionals. The department started by providing short-term training for parents for the management of children with cerebral palsy. From 2003, various RCI-approved certificate courses (which includes Advanced Certificate Course on cross disability and Inclusive Education), Diploma (D Ed Special Education- Cerebral Palsy) and degree-level courses (B Ed Special education – Intellectual Disability)

have been initiated. Teachers from government schools across the region have been trained on disability through the RCI approved Foundation Course.

Home-based training programmes for teachers and caregivers' trainings have been conducted under the National Trust. *Shishu Sarothi* has, over the years, reached out to more than 5000 professionals including doctors, nurses, RMSA, SSA, ICDS, ASHA and Anganwadi workers, through various governmental capacity-building initiatives on disability.

#### *Bharati Infratel Scholarship Programme (BISP)*

*Shishu Sarothi* is also the implementing partner for the Bharati Infratel Scholarship Program (BISP) in collaboration with the CSR wing of Bharati Infratel Limited. This programme was launched in 2016 to support the higher education of students with disabilities across all the eight North Eastern states with identified partner organisations in each state. Over 195 students across North East India have been awarded scholarships for a variety of courses and programmes.

#### **Other Interventions**

##### *Early Intervention*

*Shishu Sarothi* has been running the Early Intervention Unit (EIU) since its inception in 1987 and has reached thousands of young children across North East India, providing over 50,000 therapeutic sessions. The unit provides early detection, screening and management services for infants, high-risk babies and young children with delayed development milestones and disabilities through therapies and child-specific home management programmes.

Research in the area of child development has borne testament to the fact that the first six years are the most crucial for every child's overall development. Hence, it is essential that such services are provided to children who are at risk or have been diagnosed with one or more form of disability. The factors leading to such developmental delays include, among others, prenatal complications, premature birth, low birth weight, malnutrition, neglect and disease.

Such services ensure timely intervention and ensure that children with developmental delays: cognitive, motor, socio-emotional, communication, can enhance their quality of lives and achieve their fullest potential which in turn will encourage their

early inclusion in mainstream society. For instance, children with disabilities and their families are provided with individual assessment and evaluation in order to understand and recognise the development of gross and fine motor skills, cognitive skills, receptive and expressive language skills, play skills and self-help skills of each child, in order to work with them accordingly. There are planning and development management plans, ranging from setting individual short- and long-term goals for every child, right up to home management programmes for parents to continue working with their children on identified specific goals.

In addition, follow-up sessions with children, as per the convenience of the families, are held on a weekly or monthly basis. The programmes are reviewed and updated with appropriate need-based therapies which include physiotherapy, speech therapy, occupational therapy and special education. Free Play Stimulation programmes held thrice a year enhance the motivation and engagement of children through the medium of play.

Children from the Early Intervention Unit are provided with referral services as per the progress and individual needs of the child within *Shishu Sarothi's* Centre for Inclusive and Vocational Unit, Sparsh Unit and Pre-Vocational Unit. They are also referred to medical professionals for the control of associated conditions such as seizures and diagnostic tests like BERA and vision testing. Aids, appliances and assistive devices ranging from hand/knee gaiters, ankle-foot orthosis, hip-knee-ankle-foot orthosis, knee-ankle-foot orthosis, modified shoes etc, are also recommended.

##### *Counselling*

The Counselling Unit provides primary psychosocial support and counselling services to parents. The unit works to educate the parents, usually the primary caregivers, about their child's disability to help them cope with emotions that they may be going through surrounding their child's disability and to empower them to better manage their situation. We also create an understanding of the need for inclusive education in mainstream schools wherever there is potential.

##### *Outreach*

*Shishu Sarothi* also conducts outreach programmes in the rural areas of Assam with the objective of creating awareness among communities, identifying or screening children with disabilities and providing

information about the prenatal and postnatal risk factors for the children. At the request of members of the local community in Goalpara, weekly Early Intervention services in collaboration with a local NGO was initiated in 2014 and has continued since. Through these weekly visits, we have reached out to more than 600 children from Goalpara and its neighbouring districts as well as some districts in Meghalaya.

#### *Advocacy*

*Shishu Sarothi* carries out advocacy, activism and legal literacy on the rights of persons with disabilities through raising awareness, legal counselling, litigation and policy influencing programmes through its Disability Law Unit – North East (DLU-NE). The Disability Law Unit has been involved in awareness and sensitisation workshops or programmes for various stakeholders including Disabled Peoples Organisation (DPO), bureaucrats, judiciary among others under the Rights of Persons with Disabilities Act, 2016 across all North Eastern states. At present, we are involved in awareness generation programme on disability and the RPWD Act, 2016 with the Social Welfare Department, Government of Assam as the implementation partner at the state, zonal, district levels along with

the development of Information, Education and Communication (IEC) Materials. This initiative is the first of its kind in India.

#### *Research*

*Shishu Sarothi* has recently initiated its work in the area of research in disability-related issues from time to time to create evidence on the situation of persons with disabilities because of the unavailability of disaggregated data on various areas of disability. *Shishu Sarothi* has collaborated with the Voluntary Services Overseas (VSO) to create an SDG disability tracker focusing on persons with disabilities in the context of the Sustainable Development Goals (*Gender Equality, Clean Water and Sanitation and Decent Work and Economic Growth*) in the districts of Chirang and Kokrajhar, Assam.

Thus far, the journey of *Shishu Sarothi* has been full of mixed experiences. There have been several roadblocks, but the journey continues as a dedicated team of professionals work relentlessly towards a common goal. The organisation envisages a future where society respects and celebrates diversity and persons with disabilities live a life of dignity at par with others in all respects.



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