

Reaching Out to Rural Homes – Mobile Team Intervention for Families Living with Intellectually Challenged Persons in India

The Challenge

As a young boy, Medida Venkata Rao stayed home while his parents worked as labourers and his siblings attended school. Although he had only a mild intellectual disability, Medida was treated as if he had no potential at all. Left alone, he would play with younger children who encouraged him to misbehave. They taught him to tease girls as they fetched water. Eventually, Medida's behaviour frightened many children, and he grew rude to his family. When he became a young man, the community found Medida troublesome and shunned him – which only reinforced his bad behaviour.

While Medida was neglected as a child, others like him are overprotected or pampered. Children with intellectual impairments are often denied an education and rarely taught skills; some never even learn to eat or speak. As adults, especially in rural areas, they are unable to find productive work.

In the 1990s, a few of India's dedicated professionals recognized that people with intellectual disabilities had the right to lead fulfilling lives. They also believed that even in an atmosphere of economic obstacles and age-old cultural biases, communities and families could change how they treat people with intellectual disabilities. But how could people with intellectual disabilities in rural areas gain access to affordable training and rehabilitation services? How could parents and community members be transformed into service providers?

Meeting the Challenge

The Thakur Hari Prasad Institute (THPI) of Research and Rehabilitation for the Mentally Disabled believes that work can empower people with disabilities, even if that work takes the form of helping out at home. According to Vijay Thakur, project director of THPI's Community-Based Rural Project, the notion of work as a means of empowerment was an innovative concept for India in 1992, the year in which institute officials created a community-based programme.

The mobile Community-Based Rural Project reaches out to communities and organizes them to take responsibility for those with special needs. It provides medical and social rehabilitation, training and other services in neglected rural areas where people with intellectual disabilities rarely have a chance for independent or challenging lives. THPI committed itself to paying competitive salaries in order to attract high-quality staff, including physicians, physiotherapists and psychologists. The project strategy calls for a vocational training component that involves local volunteers who are paid a small stipend to train people with intellectual impairments, often on the job.

Today, the THPI Community-Based Rural Project relies on active community participation under the supervision of THPI's skilled staff, thereby helping an otherwise neglected segment of the population become productive and accepted community members.

The Good Practice: A mobile programme that penetrates rural villages and offers multidisciplinary services and community-based rehabilitation.



• Background •

Thakur Hari Prasad is a large organization that is the recipient of several awards. It was established in Hyderabad (southern India) in 1968 as a rehabilitation centre for children. Over the years, it has evolved into an institute employing more than 250 professional and paraprofessionals in paediatrics; clinical psychology; special education; speech pathology; psychiatry; occupational, hydro, art and music therapies and other innovative medical rehabilitation approaches. Its services focus on prevention, early detection and early intervention as well as on vocational training for people with intellectual disabilities. Its staff train trainers, arrange foster care for people in need, conduct research to develop training and rehabilitation models and advise the Government on national policy guidelines and community-based work.

The institute organizes seminars, conventions and sports events to raise awareness about the human rights of people with disabilities and advocates for integration through camps that serve all types of children. It produces for sale charts, manuals, books and audio/video tapes that deal with a wide range of subjects – from training in eating skills and horticultural therapy to education materials for people with intellectual disabilities in rural areas. Private donations as well as support from the Indian Government through the Ministry of Social Justice and Empowerment fund THPI.

• The Community-Based Rural Project •

Targeting rural needs. India's population includes more than 20 million people with intellectual disabilities. Until recently, the Government excluded such people from rehabilitation programmes. Instead, NGOs provided services in some communities but largely neglected rural areas. In India, more than 50 per cent of people with intellectual disabilities live below the country's poverty line. The situation for women with intellectual disabilities is particularly complicated. A concept of "eternal childhood" and protection of women dominates Indian culture. For example, a middle-class family is hesitant to send an adult daughter with an intellectual disability to a training programme that would enable her to go out of the home to work, explains Mr. Thakur. The family would, however, accept a training scheme that enhances the daughter's household skills.

In 1990, THPI officials wanted to fill the service gap for people with intellectual impairments in rural areas by creating a model of rehabilitation that could be replicated throughout the country. After researching and discussing strategies, THPI in 1991 started a family- and community-based rehabilitation programme targeted to rural-area people with disabilities. While the THPI model includes two small urban-based vocational training centres, its main focus is the mobile Community-Based Rural Project.

The rural project is based in Rajanadaram Mandal and serves about 36 villages. (India's division of states, which are further subdivided into districts and mandals. A mandal is composed of about 30,000 to 50,000 people.) The project's programmes in each village are time-bound, lasting two to three years. They prepare a community to take responsibility for its members with intellectual disabilities. During the prescribed time period, the programme conducts surveys, delivers services and training and provides regular supervision until the village can assume responsibility for residents with intellectual disabilities. The programme also uses a strategy of working with linkage organizations, such as primary health centres that already operate at the grassroots level.

The rural project team. Using a holistic approach to detect, identify and intervene as early as possible in the lives of people with intellectual disabilities in neglected areas, the programme's multidisciplinary rural project team pays attention to special needs for speech, language, behavioural skills development, social skills, gross motor and fine motor activities and development of leisure-time and vocational activities. The team consists of a paediatrician, speech therapist, occupational therapist, physiotherapist, psychiatrist, clinical psychologist, medical and psychiatric social workers and a special educator – all full-time employees of the institute.

Entering a village, organizing the community. When the rural project team goes into a new rural area, it solicits the support of the village leader, called the Sarpanch, and enlists women's groups and youth clubs as helpers. "We must enlist their help and empower the grassroots people; we just cannot do it alone," says THPI Director General Prof T. Revathy. As one of its first steps, the Rural Project Team conducts a door-to-door survey to identify people with disabilities. It next organizes a "camp" to assess people's aptitude and needs. Those with other than intellectual disabilities, such as vision or hearing impairments, are guided to the appropriate service or agency to meet their needs while the team targets those with intellectual disabilities.

During the assessment period, the team organizes a village committee made up of caring community members, parents of people with disabilities, teachers, artisans and other tradespeople willing to volunteer as trainers. The committee is the core support group and the key to THPI's success in rural communities. The team works constantly with the committee and trains it to assume responsibility for helping people with intellectual disabilities.

The team also identifies and works with linkage centres, specifically village-based organizations that provide a base for team activities. Linkage centres are often preschools or primary health care centres. Given that parents often go to the field or to work, the linkage centres are a place where parents can leave their children, if necessary. THPI trains the doctors at the centres to identify disabilities early and to make referrals to the team for needed services. (THPI is also training primary health centre doctors all over India in disability issues and how/where to make appropriate referrals.)

The rehabilitation plan. The team, along with a person with a disability and his or her family, develop a rehabilitation plan that can take one of three directions depending on the age of the person:

- Persons younger than 15 are integrated into local schools when possible;
- Persons who cannot take care of themselves because of severe disability or immobility receive home-based training in work skills, such as mat weaving; and
- Persons older than 15 are placed in local jobs and trained on site. Trades range from agriculture, carpentry, welding, pottery and white washing to plant nursery, cattle grazing and blacksmithing.

The committee also helps identify specific rehabilitation services as well as community members who can assist in providing services under the direction of the team.

Educational integration. Activities related to education receive the highest priority. In the absence of a preschool, the team helps establish such a school and makes certain that children with disabilities enrol in the school. Preschool enrolment begins the process of integration and fosters community acceptance of people with disabilities. Children function as an entry point in the process of changing adult attitudes. Activities in the centre focus largely on developing social skills among children with disabilities. Financial assistance to the preschool, as with the community-based programme, is time-bound and lasts for up to three years. Beyond the preschool, team counsellors work with primary school teachers and teachers at other levels to prepare them for students with disabilities who will eventually integrate into the regular classroom.

Working with families. If necessary, the team works in the home of children and adults who lack social skills; in this way, the team also counsels the entire family in how to help a person with a disability gain some independence – whether related to eating skills or house or agricultural work. Parents and siblings often become assistants in providing therapy for a family member with a disability. Workshops conducted for family members and other community volunteers help demonstrate how to train the family member with disabilities in the skills needed for employment. “In some villages, the grandparents play a key role,” according to Prof. Revathy. “They can be overprotective and not want the disabled person to go out. By training villagers, they can convince families and grandparents to give more independence to the disabled children and young adults.”

Additional team activities. Team members provide family, marital and behaviour counselling. They set up community development funds for use by families with a member who has a disability. Team members also help families obtain financial resources through bank loans and other government assistance. They raise awareness in families and communities about disabilities and about how people can help each other. They encourage the creation of support groups that involve people both with and without disabilities.

The team works with the village for two to three years before it moves on to develop programmes in other villages. During the active phase of village involvement, the team visits the village and provides or supervises service delivery approximately every three weeks.

Vocational training. Vocational training usually occurs on the job. For a period of one to three months, special educators train job coaches and instructors – usually women and youth from the village committee or people skilled in a particular trade – in how to teach the technologies appropriate for people with intellectual disabilities. Job coaches usually receive a stipend but not a salary. The type of training changes from village to village, depending on the local market and a village’s economic activity. The team or job coach negotiates with employers to identify training slots for disabled people. Once a trainee has reached a level of acceptable functioning, a wage is negotiated based on ability and output.

The team follows up on placements and visits individuals on the job. Placements are typically with small, private sector businesses common in mandal settings and often include positions in bricklaying, carpentry, animal raising, agriculture, tailoring and horticulture, to name a few. Some individuals work in the fields or help with home and community chores.

How the Rural Project Team Helped Medida

Medida, the boy perceived as troublesome by his family and community, met the rural project team during a village survey. At that time, he was 23 years old. The team found him hyperactive and unable to engage in constructive activities. He used unacceptable language and was physically abusive to his siblings. At the same time, the team described him as quick in acquiring skills, capable of good concentration and responsive to social reward. He showed real potential, and the team wanted to work with him to develop it.

Medida took part in training to learn how to take care of cows. By taking advantage of the community development fund started by the project, Medida's father bought a buffalo. It became Medida's responsibility to look after it. Being occupied in something productive and assuming responsibility seemed to result in positive changes. At the same time, the team worked with Medida by using reinforcing and other behaviour change techniques while encouraging family members to include him in household decisions. Community members also were involved.

Social workers counselled Medida about socializing outside his family. He volunteered to join a newly set up youth group in the village. At first, the group refused Medida entry because of lingering negative attitudes. The team talked with the youth group, which agreed to give Medida a chance. The youth group involved Medida in its main task, monitoring village sanitation. He learned about the importance of sanitation for good health and was further assisted by a village support group that helped with the monitoring.

The village children, who used to fear or tease Medida, gradually accepted him. During festival celebrations, the village leaders recognized his achievements. Now, Medida no longer stays at home alone. He often helps his father earn money by selling agricultural products.

• The Centre-Based Urban Programme •

THPI built two vocational training centres in urban areas to train, find job placements for and provide ongoing support to people with intellectual disabilities. Though most trainees come from urban areas, the centres also serve some rural residents and make hostel accommodations available for 30 trainees. Enrolment totals about 45 trainees each year, and each skills unit accommodates seven to eight people. Courses can last up to four years. Training takes place in classrooms; skill areas include carpentry, horticulture, offset press, letter press, book binding, tailoring, candle making, baking, home management, shop keeping and commercial cooking.

Job coaches work with trainees and are responsible for finding on-the-job training opportunities in, for example, a tea shop or chocolate factory. The job coach works as frequently and for as long as the trainee needs his or her assistance.

Accomplishments

Officials at the Thakur Hari Prasad Institute of Research and Rehabilitation believe that employment is a basic right. Therefore, they pioneered THPI's approach to prepare adults with intellectual abilities for entry into the job market. At the start of the programme in a given village, some trainees lack even the ability to feed themselves, but through participation in the programme they can complete various tasks and take pride in their considerable achievements. Other accomplishments include changes in family members' perceptions about the ability of people with intellectual disabilities, increased community acceptance of people with disabilities and empowerment of community members through the delivery of training to disabled people. And while the lack of job openings means that many people are not always placed in jobs for which they received training, the work behaviour developed during training facilitates individuals' adjustment to the work world and enhances their chances of success in any work situation.

Between 1991 and 2001, the community-based programme worked with 403 people with disabilities. Of them, 94 received skills training, 69 are now employed full time, 81 still apprentice, 91 receive home-based development training and the remaining 68 are still undergoing assessment.

In the same period, the centre-based programme has trained 146 participants, provided 110 people with job training and others received home-based support. The centre-based programme is intentionally small due to THPI's emphasis on working in rural areas.

Lessons Learned

Working with individuals with a range of intellectual disabilities and in different settings requires a strong multidisciplinary approach. Given that THPI set out to create a model that lends itself to replication, THPI officials have paid close attention to the programme's trials and errors. In developing a successful community-based programme, THPI has learned from the following experiences over the past decade:

Training core community workers reaps long-term returns. Typically, the rural project team works in impoverished communities. While many community residents are willing to help their fellow citizens, individuals' willingness to continue involvement over time requires some form of remuneration, including fees paid to community-based trainers. In order to sustain their interest and investment of time and energy, local trainers also need incentives in terms of raw materials, tools, maintenance of equipment and so forth.

Human resource training is a prerequisite for effective intervention programmes. Both grassroots trainers and local supervisors play important roles in ensuring the success of community-based programmes and overseeing an individual's vocational rehabilitation. Trainers and supervisors need to learn about disability issues as well as how to work with people with disabilities and how to manage a community's rehabilitation programme.

Success requires a strong community base. To sustain community-based interventions, a programme needs to be people- and community-centred as well as linked to mainstream programmes, such as nonformal education or adult literacy courses, rice distribution schemes and nutrition programmes.

Community centres are still needed. Not all interventions for people with intellectual disabilities can take place in a home setting. With the help of a trained paraprofessional or community worker, both children and parents can receive rehabilitation training and education at community centres. Group training saves time and money and results in needed social interaction and group support.



Looking Forward

THPI's plans call for expanding the ongoing programme by undertaking several additional activities. In addition, THPI expects to maintain and develop new partnerships with employers in order to sustain and identify more job opportunities. It also recognizes that to mobilize resources and reach more people it must network and develop additional linkages with NGOs and various agencies of the Government, particularly those with education and health oversight. The programme needs to reach out to more villages, perhaps necessitating the creation of another rural project team. Further, THPI sees one of its roles as promoting strategies that will encourage the Government to replicate the programme in other parts of the country. Finally, THPI plans to research and document the rural project team's success stories as a means of raising awareness and inspiring others.

Replication

Many aspects of the Community-Based Rural Project are worthy of replication whether or not the entire project is copied. In fact, the project was designed for easy replication in developing countries. It does not require facilities and does not incur overhead costs, other than for team vehicles. However, to ensure high-quality professional team members, a large investment in salaries is essential. Project success lies in building linkages with existing resources to meet the skill development and education needs of people with intellectual disabilities in rural areas. The central component is a village committee that works with the rural project team in surveying the population of people with disabilities and understanding their needs.

For More Information

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