

Wings to Fly – Children with Cerebral Palsy Find Their Way into Independent Adulthood in India

The Challenge

In eastern India in the late 1980s, parents watched with immense unease as their severely disabled children advanced toward high school graduation. They wondered, “What next?” Their children had been educated but in a protected cocoon – a setting of the Centre for Special Education at the Indian Institute of Cerebral Palsy (IICP). Parents knew that they had to help prepare their children for a less sheltered life beyond the IICP’s doors. And the young people wanted to learn the skills needed to earn a living and gain more independence. However, eastern India offered no opportunities for vocational training for persons with cerebral palsy and other substantial disabilities.

Meeting the Challenge

The IICP administrators could not ignore the needs and aspirations of their students. After several rounds of discussions with parents, students, former students who had found employment and officials from other centres working with people with disabilities, the administrators recognized that building a vocational training centre appeared to be the only solution. “A sheltered workshop was not an option,” says Reena Sen, IICP deputy director. “After the discussions, it was our organization’s conviction that a sheltered workshop is not conducive to helping people be included in the community. We did not want to segregate.”

The IICP Adult Training Centre (ATC) opened in 1992 and remains a unique example of a comprehensive rehabilitation centre because it:

- Provides optimum but time-bound training for open or self-employment through links with businesses, government and mainstream universities;
- Helps young people learn to cope on their own, with guidance and counselling for both trainees and family members; and
- Involves a family member in training alongside students interested in developing family-based businesses.

The Good Practice: With input from disabled people and their parents, a comprehensive adult training centre developed that teaches marketable skills, using appropriate adaptations and family involvement.



• Background •

Led by a parent of a child with cerebral palsy, the Centre for Special Education began operation in 1974 in Calcutta as a small school for two students. It grew into a national resource centre and major training organization and changed its name to the Indian Institute for Cerebral Palsy. Through its varied services, it now reaches more than 3,000 families. The IICP's main objectives are human resource development, providing needs-based training, undertaking applied research and developing service models for persons with cerebral palsy and their families in both rural and urban areas.

Those services, which are available to trainees in the ATC, provide a holistic approach to helping young people achieve independent living; they involve early intervention, therapy, family support and community-based rehabilitation. In addition, adult clients have formed a self-advocacy group to push for better implementation of disability policies and to change public perceptions about people with disabilities. Adult clients also lobby local authorities for improved mobility and accessibility in the community through, for example, bus access and the construction of ramps and lifts in buildings.

• Creating the Adult Training Centre •

Market analysis. In 1991, before creating the ATC programme, the IICP commissioned the reputable mainstream Indian Market Research Bureau to analyse what type of employment opportunities might be available for people with disabilities and which high-demand products could become the focus of its vocational training options.

At the same time, it organized workshops with representatives of industries and corporate businesses to discuss employment opportunities and ideas for vocational training. As a means of promoting the capabilities of workers with disabilities, the workshops highlighted success stories of people with disabilities working in open employment. At the end of one workshop, a company came forward to offer a contract for work: Bata India, a multinational company that produces shoes, was willing to engage ATC trainees in printing artwork on its shoe in-soles. Other companies offered financial support while the multinational ITC Ltd. offered computer hardware and software. Based on the

companies' interest and the market analysis, the ATC set up three training units – printing, catering and computer skills.

Instructors. The ATC hired and trained professionals in the areas of printing, catering and computer skills to teach students with multiple disabilities. The ATC staff now also includes unit supervisors, social workers and a vocational counsellor.

Curricula based on courses in mainstream institutions. The IICP bases its computer training on the computer curricula of the Department of Adult Continuing Education and Extension, Jadavpur University in Calcutta. The university's recognition of the courses allows IICP graduates to receive a certificate from the university. Though trainees learn in a segregated environment, the approach represents a step toward providing equal academic standards to people with disabilities.

Funding. A foreign agency donated about US\$60,000 for initial construction of the ATC and the purchase of basic equipment. The IICP now finances its services through grants from the Ministry of Social Justice and Empowerment, nominal fees paid by trainees and project-related funds from donor agencies. In addition, money earned in the printing and catering units is allocated to the operation of the centre.

Fees. Trainees live at home and pay a nominal fee (about US\$10) for courses. Needy trainees are granted fee waivers and sponsorships. A bus service transports some trainees to and from their homes for a fee; others travel independently.

Course period. Each training unit brings together 12 to 16 students; the teacher/trainee ratio is 1:10. The training period varies from 18 months to 2 years, depending on the needs of the trainee.

The trainees. Not all student trainees have cerebral palsy. The ATC works with people who have hearing, speech and mobility impairments as well as with those with learning difficulties. Students are mostly graduates of the IICP's Centre for Special Education who transfer to the ATC at age 18. But young adults from other non-IICP programmes are also accepted. ATC trainees come from all socio-economic backgrounds, mostly from Calcutta and the neighbouring districts from where daily commuting is possible.

• Structure of the Programme •

Choosing a skills course. Every potential trainee undergoes a period of initial assessment. Students from the IICP Centre for Special Education spend two hours attending the ATC twice a week in their final six months of school. They are assessed for independence in personal care, social skills, work-related behaviour and literacy and numeracy competency. External candidates, primarily referred from the IICP's Outpatients Division, spend two days a week for two months undergoing an assessment.

The trainees participate in both the printing and catering units during the assessment period, allowing counsellors to observe them in a work setting and permitting both families and trainees to make informed choices. ATC staff members participate in meetings with a trainee and his or her family to help the trainee select a course according to his or her interest and capability.

Following placement in one of the training units, trainees and parents, either in groups or individually, meet with staff in six monthly assessment meetings to discuss progress, difficulties and future goals.

Adaptations in the Classroom

Adjustments in furniture and seating are a priority in the classrooms, but adapted implements and tools are kept to a minimum so that trainees are prepared for real-world work situations that most likely will not resemble an adapted learning environment.

If there are any problems regarding access, handling of equipment, seating or furniture, then physiotherapists and occupational therapists work with trainees with physical difficulties to adapt the tools and make the work environment accessible.

The Computer Unit uses a variety of specially adapted software and hardware donated by private organizations. Different types of switches associated with computer hardware make it possible for profoundly physically disabled users with poor hand function to use another part of the body that they can control – eyes, knee, foot, head. For instance, the “stay down” software converts the double key operations on the keyboard into single key operations while a key guard allows easier access for people who do not have good motor coordination in their fingers.

Vocational training choices. The training units focus on skills training through instruction and work experience in response to the orders the units receive from the public for various products. (The ATC units do not operate as production centres and thus do not solicit job orders. However, people hear of the service from others, through visits to the ATC or media attention, and place orders for catering items, printed material and so forth.) Students learn to share tasks and compensate for each other’s limitations and/or build on strengths. The skills training is organized into the following three units:

- In 1995, the IICP switched the printing skills in the Printing Unit from leather work to silkscreen printing, stationery printing, spiral binding and lamination. Consequently, Bata, which had been providing the unit with work-experience contracts, transferred its in-sole printing needs to a home-based unit run by a family with two IICP graduates. Their mother also trained at the IICP to learn printing skills along with her sons. The Printing Unit supplies all cartons and napkins with the IICP logo for use by the Catering Unit. Trainees also create invitation cards and print festival messages on the greeting cards that the IICP sells as a fund-raising activity.
- The Catering Unit teaches trainees to cook for themselves, their families and others either on their own or under supervision. The work experience involves orders for sweets and baked goods or staff lunches and meals for special events.
- The Computer Unit courses cover office and database management, desktop publishing, Web design and financial accounting. The courses were established in collaboration with the Jadavpur University in Calcutta.

Social skills. The IICP places equal emphasis on occupational skills and social, independent living and consumer skills. Non-tangible skills such as learning to be responsible, coming to terms with a disability, making friends and social contacts, are as important as specific vocational skills for coping with the outside world. Social workers address these topics in group and individual sessions. Techniques used for group counselling, which are conducted once a week for social skills training, involve discussions, peer interaction, role plays, audio-visual presentations, brainstorming and case study presentations. The sessions include field visits to factories, workshops, printers, bakeries, catering businesses and computer companies to prepare trainees for working in those settings.

Individual counselling is arranged if and when required to help a student cope with personal and emotional problems or training and work-related issues. Joyeeta Ganguly, for example, a young woman with a hearing impairment, had a training placement in a computer software firm. Initially, her colleagues were hesitant to give her any work because they were finding it difficult to communicate with her. Her ATC supervisors contacted the employer and suggested that her colleagues use written instructions as much as possible. The solution enabled Joyeeta to complete her placement successfully. She graduated from the ATC and now works as a computer data entry clerk for one of India's largest tea-producing companies.

On-the-job training. During the final three months of the programme, students seeking open employment can participate in an internship in industrial and private enterprises, though without salary or stipend. Initially, unit supervisors and ATC social workers monitor the training placement on a weekly basis, then fortnightly and only once during the final month. For those hired for full-time jobs after completing their internship, the once-a-month monitoring continues for about six months or longer, depending on the situation. Not all internships lead to a job offer, however.

Working with the family. When a trainee chooses self-employment, a family member participates in the same skills training, which is a condensed three-month programme that focuses on specific tasks and matters dealing with setting up and running a particular business. If a family decides to set up a home-based enterprise, only one family member undergoes training.

In addition, ATC staff members provide family members with information about income generation, loan facilities, crisis management and organizations that deal with disadvantaged groups and the rights guaranteed by the Persons with Disability Act, 1995. The IICP assists families applying for bank loans by offering guidance and advice on how to write and submit a loan proposal, including budget estimates. A staff member accompanies families during meetings with bank officials, when needed. The IICP helps self-employed graduates secure orders and advises them during business management crises, even years after they have left the programme. Counselling is available when needed.

• Other Services •

Support and recognition for employers. Once a graduate is hired, IICP trainers work with employers to help solve job-related problems that may arise. Services may involve visits to the workplace or simply a telephone call. The IICP acknowledges employers who hire persons with disabilities in its publications. The IICP also invites employers to participate in and speak at conferences, seminars, concerts, sports events and graduation ceremonies.

Training for trainers. The ATC welcomes trainers from different organizations in the field of rehabilitation who seek to upgrade their skills. During an intensive one-month needs-based programme, they train alongside people with disabilities in order to gain knowledge and practical experience.

Alternative training. For young people with substantial physical difficulties and profound multiple impairments who cannot participate in vocational training, the ATC provides an Adult Learning and Leisure Unit for continuing education and activities. The programme includes, at present, 35 former students of the IICP's Centre for Special Education who attend two or three times a week for as long as they like. The available activities allow participants to continue their education in literacy and numeracy or simply to pursue hobbies or personal interests, such as painting, writing and poetry. For adults with severe learning difficulties, the programme includes augmentative communication, learning enhancement and leisure skills.

Trainee Stories

- I had always felt scared about my future,” recalls Hiram Jyoti Rakshit, a cheerful person who enjoys dance and acting. Hiram, a 24-year-old man with cerebral palsy, is now self-employed, working with his mother in their home-based business providing screen and press printing and office stationery. He was enthusiastic about screen printing from the start, even though he has the use of only his left hand. Individual counselling helped him recognize his positive abilities, including entrepreneurship. He was encouraged to set up his own business in August 1999. His mother volunteered to work with him and underwent practical training in silkscreen printing and marketing. She now concentrates on the “outside” jobs such as marketing and delivery of printed materials. In 2000, his former IICP trainers urged Hiram and his mother to expand their business and apply for a loan from the National Handicapped Finance Development Corp., which is a funding agency within the Ministry of Social Justice and Employment that promotes economic and development activities for disabled persons.
- Barsha Bhattacharya has severe physical and speech impairments. She has cerebral palsy and is a wheelchair user. She communicates with a low-tech augmentative communication word and letter-based terminal in her mother tongue, Bengali. She is a talented poet and started expressing her feelings by writing poems with the help of another adult by pointing out words and spellings on her terminal. She has recently started using a more versatile computer programme – Clicker 4 – and an adapted switch that enables her to compose poetry independently. She is confident and active and plans to publish her literary work.
- My poor hand control and jerky movements made it difficult for me to do printing,” explains Souvik Choudhury, 43, who has cerebral palsy and who enrolled at the ATC in 1997. “However, the professionals at the Indian Institute of Cerebral Palsy noticed my affinity for good public relations and business aptitude. After a review of my abilities, a tailor-made programme was devised for me. I was trained on the theoretical aspects of printing, marketing and office management.” Within a year of completing his training, Souvik started Sai Prints. He has a trade license and his own bank account. His job calls for him to obtain printing orders, ensure that the work is completed and then deliver the order to the client for a commission.

Accomplishments

Since 1992, the IICP has completed five training cycles. An average of 25 trainees graduate during each cycle. The number of trainees attending at any one time increased from 28 in 1992 to 50 by August 2002. In terms of individual achievements since 1992:

- Of the 134 total who have completed training, 47 (13 women), or 35 per cent, found jobs in open employment and 46 (six women), or 34 per cent, sought self-employment. Forty-one per cent (seven women) are currently participating in internships or have gone on for further studies in computer courses. The types of jobs include work in a printing press, offices, small restaurants, snack bars, bakeries and IICP's Catering Unit as well as data entry, home-based printing and catering.
- Six home-based printing businesses for which the IICP trained a person with disabilities and another family member are successfully operating.

Lessons Learned

"There is a real commitment to team work in this organization," says IICP Deputy Director Reena Sen. "There is a shared belief and faith in each other's abilities and strengths. And there is realization that each and every person in the organization plays a crucial role in the quality of services that we offer." The IICP's achievements provide various insights:

Discussion of vocational training choices for a young disabled person should be initiated around age 12 or 13 and not at age 18. The early discussion of vocational training choices helps families and professionals identify a long-term goal toward which they can work. In addition, training can address appropriate work-related behaviours, relevant skills and knowledge and address barriers.

Support counselling may be needed for families of workers hired in open employment. Expectations of the family and of the adult with disabilities are sometimes too high regarding expected salary and other terms of employment, such as transport and leniency in leave regulations. When the job does not meet family expectations, the family does not value the job, posing barriers to the adjustment of the person with disabilities in the workplace.

Despite specific-skill training, employment in another field may be necessary. The economic situation may limit the lack of available jobs in the area of a trainee's specialization and thus necessitate rapid adaptation. If a suitable job for a graduating trainee opens up, the ATC will provide additional instruction to help that person pursue

the opportunity. For example, two trainees who trained for printing work but experienced difficulty in finding open-employment positions subsequently trained for laundry services, which resulted in their finding full-time jobs.

More emphasis on socialization skills is needed during the training period. Acquisition of social graces, daily living and personal hygiene skills and the ability to work with a team or to take criticism can be factors that facilitate inclusion in the workplace.

For access reasons, home-based self-employment options have become a necessity. Many people with disabilities have the intellectual capacity and the skills for open employment, but difficulties with physical access in offices and in the use of public transport pose insurmountable barriers. Some employers are sensitive to these issues and provide needs-based facilities, although they are rare. Many people see their home environment as more user-friendly. They are “independent” in the sense of using their knowledge and skills even though they are assisted by family members in a home-based enterprise.

Family involvement is pivotal in the rehabilitation process, though it can also prove to be an impediment. The involvement of a family member in work with former trainees creates successful businesses, but the person with the disability should remain for production activities. Increased responsibility leads to greater self-esteem, and the individual’s contribution to the household budget translates into greater social respect and acceptability.

Parents need help in clarifying their hopes and expectations and in recognizing barriers and limitations. The socio-economic context and constraints of a family can be major determinants in the choice of training and employment for a young person with disabilities. A close, two-way interaction between parents and their disabled child and professionals is needed to set goals and assess family expectations and commitment levels.

Home-based units are sometimes difficult to sustain. Many former trainees struggle to keep their businesses afloat in an environment of strong competition or a slow-down of orders after business start-up. Sometimes the person with a disability cannot keep up with delivery schedules. Family members can help, but they should not assume the disabled person’s role. Discussions with the family and reminders about training objectives and the individual rights of people with disabilities must continue during IICP follow-up visits.

Looking Forward

The IICP's decision to adhere to the teacher/student ratio of 1:10 in the Adult Training Centre has led to the delivery of high-quality training, but it has also created financial constraints that prevent the organization from offering the competitive salaries that would allow it to increase staff and thus extend its services to more people. The IICP plans to continue lobbying at the policy level for an increase in government grants. It is also looking for other ways to increase its financial self-sufficiency and is considering setting up a production unit for catering and printing products. The IICP intends to upgrade its facilities in all training units by seeking donor support.

It also is aiming to expand its training-for-trainers programme for instructors in mainstream training centres, particularly in district and rural areas, thereby widening the scope for greater inclusion of adults with disabilities.

In addition, the ATC's Adult Learning and Leisure Unit – in collaboration with the Department of Adult, Continuing Education and Extension, Jadavpur University and the National Institute of Open Schooling – will offer continuing education and adult literacy programmes through certified short courses for persons with severe physical and communication difficulties.

Replication

Funding and family involvement are two important conditions when setting up a training centre that follows the IICP model. A large centre is not the only venue for offering vocational training. It is possible to reach people with disabilities indirectly, particularly in rural areas, by motivating and providing training for trainers in rural-based organizations. Some ideas to keep in mind when establishing a training centre like the IICP or simply offering training include the following:

- Examine the market to identify jobs, opportunities and business trends. It is essential to understand the realities of the marketplace, including hiring biases. Public education and awareness campaigns may be necessary to create a more open, disability-friendly environment.
- Establish links with businesses, associations, marketing agencies, mainstream educational institutions and the government. These links are valuable in raising awareness and broadening employment opportunities as well as in ensuring higher-quality training. In an environment characterized by a slow-growing economy and strong competition for jobs, such links can prove advantageous.
- Integrate some type of work experience into the training classroom. It might make sense to consider a production unit or a mechanism that generates a level of income sufficient to make training centre services self-sustaining while providing work experience.

- Include in the curriculum a training unit on social skills, finance and marketing as well as some type of internship or on-the-job training in local companies. Each activity needs careful planning, and trainees need preparation and support for each component.

For More Information

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For more information on high-tech augmentative communication systems, IICP suggests:

- Quest Enabling Designs Ltd. (United Kingdom)
- Toby Churchill Ltd. (United Kingdom)
- Penny and Giles Computer Products Ltd. (United Kingdom)
- The International Society for Augmentative and Alternative Communication (Canada)