SSNI's MISSION

WE WORK WITH:

People who have cerebral palsy, other neuromuscular and multiple disabilities (and others, where there are no facilities), and their caregivers and communities. We will work especially with those who are further marginalized by poverty, stress, the severity of their disability, or other factors.

WE WORK TO:

Provide the rehabilitation and personal development services and support our students and trainees need in every area of their lives, maximizing appropriate integration.

Create the possibility for an optimum quality of life for our students and trainees and their families.

Facilitate the empowerment of people with disabilities, their families, caregivers and communities; honouring their capabilities rather than focusing on their disabilities.

Move into the community, working with people in their own environments whenever possible.

WE WORK BY:

Developing holistic and cost effective services and prevention strategies that are suitable for a poor and developing country, using the abundance of resources and motivated people available in the community.

Striving to express the highest ideals in service, work, ethics, management, interpersonal relations, and policy making. Reaching high professional standards in all aspects of our work, remembering that our purpose is to help people who are disadvantaged.

Involving people with disabilities and their caregivers in all aspects of our work, and the decision-making processes that govern their lives.

Facilitating increased self-advocacy by people with disabilities.

Using a collaborative and multi-disciplinary approach to program planning, operating and managing.

Networking with other groups, with a spirit of generosity, cooperation and understanding, in order to maximize services for the disabled. Raising awareness, exposing other social activists and the public to the rights, needs and capacities of people with disabilities. Embracing other social and human rights concerns/causes keeping in mind our primary objectives.

"The problem is not how to wipe out all differences, but how to unite with all differences intact."  

Rabindranath Tagore
SSNI

A society for people with cerebral palsy and other disabilities, and for their families and those who care and work with them.

It is the person rather than the disability which is at the heart of SSNI's thinking and activity.
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The stories and descriptions you are about to read are a portrait of the people and the work of the Spastics Society of Northern India (SSNI). At the time of its beginning in 1978, SSNI was a small special education school, created by three women in Delhi who had been inspired by the work of the original Spastics Society, India (SSI) in Bombay. Within a few years, we created a project to work with children and families for home management, and in 1981, a rural rehabilitation project in Doyalpur, Haryana. New projects and programmes have kept evolving as a natural outgrowth of our increasing understanding of the needs of the people we work with and for. In 1984, we started a school to train special educators and rehabilitation therapists; then began a work training centre in 1985, and a resource centre to design and produce the special aids and appliances our students need.

The evolution of our work has involved a change in focus, especially during the past few years. From a thrust on high standards of professionalism, our focus now encompasses a disinvestment of “professional” power, whenever possible, to bring about empowerment of people with disabilities, their caregivers and communities. We have moved from being primarily a centre-based institution, and are increasingly going into the community to work. We have added indirect, and “apex” level activities to the primarily hands-on direct services which had previously defined our work. The Group on Awareness Raising and Publicity (GARP) for example, began public education activities during 1994. NIDDR (Networking, Information Dissemination, Disability Development and Rights Advocacy) is a project we began in 1995, combining professional networking, legislation and advocacy work.

During the past few years, SSNI has faced many challenges, and in 1990 we began a series of discussions to come up with creative and new ways to improve our work. In order to cope with our challenges we have had to make hard choices and weather storms. We began to resolve problems consensually, and in a way that has forever changed our vision, mission and our approach to work.

It was a major adjustment for example, in the mission of a small organisation, to begin to do research on ground realities and discursive analytical writing, information dissemination on national policy and legislation, and advocacy work. Adding this work to the service delivery and major training projects that were already in place and requiring our full attention was a difficult job. We had to renew our personal commitment and recharge ourselves to take on what was often stressful work done by a few people in addition to what were already full work loads prior to the development of the new projects.

We were propelled into activism, when we coordinated collective action by 150 NGOs, in 1994. We faced an impending crisis for rural rehabilitation and training programmes all over India, as a result of inappropriate legislation within the Rehabilitation Council of India Act of 1992, which had sections that went against the present wisdom about rehabilitation training in developing countries. This legislation was initiated by the government department that was also our paymaster; our action was controversial and involved some risks. We want ahead, deeply believing in the critical nature of this work for legislative changes to protect the rights and opportunities for people with disabilities in our country. The new leadership role we were taking required intensive study and influenced all of our work. We became an active part of a growing community of like-minded organisations, working with people across disability. We felt strengthened by help from organisations working with and for poor women, for income generation, and from our work with health care reformers, legal and political activists.

The macro level study and understanding has enriched us; it has helped us to deepen our focus on poverty and to look for ways to strengthen the multiplier effect of our intensive training work. An ongoing consultation by Ms. Sue Stubbs (Overseas Disability Advisor for the Save the Children Fund, an inspired and experienced rehabilitator who was evaluating our work related to a large grant from the Overseas Development Agency (ODA) from 1993-95), has also provided us with valuable input and important guidance for the changes we are making. It is one of the factors which has led us to increase our focus on working with people in poverty, to develop partnerships with parents and a wide range of professionals and organisations, to concentrate on apex level activities in addition to direct services, and to decrease our emphasis on professionalism.

Unmet Needs of Indian Persons with Disability

95% of India's persons with disability, poor persons, and other people who are severely disadvantaged live without a chance to access opportunities and without many of the basic rights that would give their lives a human quality. Many are living lives of quiet desperation, with no windows to the world of possibilities which others take for granted. The pain and suffering associated with disability is immense. For an individual with an impairment like cerebral palsy, lack of
knowledge and appropriate intervention can result in a total absence of any recognizable positive quality of life, and in increasing suffering and an early death. The extremely low levels of stimulation for disabled persons who receive no rehabilitation or education or other services, leads to a life where there is no discernible difference between childhood, parenthood or old age. They can expect only further marginalisation in the future as economic reforms coupled with structural adjustment programmes lead to resource crunches for the public development sector.

As socio-economic disparities widen at an alarming rate in our country, we have felt the necessity for greater and wider outcomes for our work and for our sustained involvement, where possible, in macro level policy, planning and implementation. We want to take every chance to support positive governmental efforts and to dissent in an non-confrontational but influential manner whenever necessary. We have structured our work to facilitate dissemination of information about the needs of persons with disability, to engage in collective action with others, and finally, to empower persons with disability to play a more active role in our democracy.

The Need for Skillful Empowerment Work

Recently, we have been distressed by the experience of several of our alumni with disability who have been well rehabilitated by our previous professional standards, but are today living at home, unemployed, with little social interaction and few opportunities for recreation and outings. Even those alumni who are fulfilling their potential, may experience immense suffering inflicted by a society which prevents disabled people from equal participation by negative attitudes, inaccessible buildings, and discriminatory policies.

Our new way of thinking has led to changes in all our projects. Today we include regular workshops on human rights, legislation, legal and civil entitlements for persons with disability and their families, and self advocacy training for students with disabilities. We work to develop skills in public speaking for students/trainees to function more independently in the varying communities they will live in as adults. Indian spiritual philosophy, teaching other-centeredness, responsibility as citizens, and action for other disadvantaged groups is a component of the rehabilitation curriculum. The involvement of students has ranged from action for Tibetan refugees and construction labourers’ children to support for acutely ill children in hospitals.

Self Help

Today, the promotion of self help has become basic to SSNI’s approach to its development work. This can range from training caregivers and building rehabilitation activities into a mother’s daily activities, to working systematically to develop parent support groups and associations. SSNI acts as a resource for providing professional training in management, fund raising and rehabilitation. In its work force of over 300 workers, approximately half are professionals and half are trained volunteers. An additional 90 or more professionals provide free consultancy to SSNI. The majority of the volunteers come from community service and self help groups. Formal rehabilitation training for community volunteers makes them a valued support to the family. Families often move from positions of despair and intense suffering, through to grateful dependence and finally to real ‘empowerment’ as they learn to take responsibility for themselves. It is the experience of organisations working with self help groups of craftsmen and poor women that it is often useful for the organisation to be accessible to such groups for crisis management. And to influence the process of development if there is the tendency for the group to lose its initial vision of equal mutual support of all its members. We believe this is a sustainable way of growing. SSNI has recently supported the development of nine self help groups and organisations of parents, three support groups and one self help group of adult persons with cerebral palsy or multi-disability called DOSTI (meaning friendship).

Time Bound Expansion

The Government of India, Misereor, and (mostly) Overseas Development Agency (ODA) funding allowed the much needed and dramatic expansion of services, vision and of physical space to house the School of Rehabilitation Sciences, new projects for advocacy and awareness raising and expansion of our existing services. Most valued and appreciated were further inputs by ODA, supporting and guiding us in planning and funding for human resource development.

These resources have made it possible for 20 SSNI coordinators to have direct exposure to community based rehabilitation projects in Africa, South East Asia and China, as well as research training opportunities in the U.K. during 1994-95. (Approximately 10 Indian study tours are made yearly by SSNI professionals and SRS trainees to community based rehabilitation projects and successful development projects for poor women and children in agriculture and employment in urban slums and rural areas.) SSNI's
management was strengthened by excellent consultancy for improving our programme evaluation, monitoring, and for training SSNI’s workers in management skills. Without this, and due to increasing work loads, there was a risk of SSNI losing its initial drive and quality in work. An entirely new management structure, allowing for collective leadership has been one major result, and an important part of SSNI’s process of change.

**Sustainability**

As persons with disability in India are almost completely excluded from even the most minimal opportunities, there will be a long term need for an agency like SSNI which is working at the macro as well as micro levels in service delivery, training, awareness raising, and advocacy in rural, urban and urban slum areas.

SSNI plans to limit direct expansion and expand networking, advocacy and awareness raising in the future, because we see the inherent risk of our relatively small voluntary organisation reducing its quality of impact, drive and commitment if we expand into a much larger institution. As the government and other funding agencies realize the necessity of information dissemination, advocacy, networking and awareness raising so as to achieve what we call a multiplier effect, funds are becoming increasingly available for these activities. SSNI will most likely have access to high quality expertise making expansion in these areas easily possible.

Our future expansion plans also require that we link extensively with other groups, institutions and individuals. SSNI is at the time of this writing, networking with 250 groups and organisations. We perceive an urgent need today for links with organisations for rural development, poor women and children, and income generation. A convergence of development efforts seems essential when people with disability have so many unmet needs, and there is a severe crunch of resources.

SSNI’s rural and urban building expansion is complete now. Its future financial need for capital assets will be comparatively small. We are working towards diversifying financial sources for recurring expenses with a view to lessening reliance on Government grants. Forty percent of our recurring expenditure already comes from fund raising projects, like sale of greeting cards, stationery products by the VWTC, benefit performances, donations and income from investment. We hope to expand the organisation’s financial assets to further self reliance in recurring expenditure funding and to ensure sustainability of our projects.

The 1990’s are harder times for development agencies like SSNI than were the earlier reformist decades of its initial work. But the injustice of the socio-economic disparities that exist today has sharpened up our values, and reinforced our will to raise awareness in communities about the many unmet basic needs of persons with disability. We must actively recruit professionals and others to work as volunteers or to accept lower than market wages. These staff are usually highly dedicated. But such recruitment is more challenging and demanding of time and effort. It results in higher worker turnover, as professional persons who are dependent on other family member’s salaries must leave when the other wage earner’s situation changes or the family must move.

**Faith in the Human Spirit**

SSNI, however, is more at peace today with alternately swimming in troubled waters and touching dry land infrequently. It seems the need of the hour during this age of materialism and an individualism that sometimes rejects the right of all humans to a measure of equality. The foundation that is the greatest strength of SSNI is a philosophy that tries to amalgamate the ideals from all the religions, and the humanist beliefs of its workers and clients. Sathya Sai Organisation members, Christian priests and activists, Sikh preachers, the Dalai Lama, Buddhists, and Marxian socialists have all become a part of SSNI’s extended family, working along with us and influencing our culture. These ideals are integrated at weekend retreats, (for example in Anandgram in 1994) and consensus is reached about values at meetings about the vision and mission of SSNI.

The development of many of these humanist ideals and spiritual practices are part of our personal development work and the stress relief work for our clients and their caregivers. The challenges of 1994 and 1995 have deepened our belief that this aspect of our work is critically important in order for SSNI to endure and for our clients to develop confidence and enthusiasm while they struggle for a human existence.

*Mita Nundy*
SSNI ACTIVITIES OVERVIEW

DIRECT SERVICES

CENTRE FOR SPECIAL EDUCATION (CSE)

INTEGRATION CELL

HOME MANAGEMENT PROJECT (HM)

VISHWAKARMA WORK TRAINING CENTRE (VWTC)

RESOURCE CENTRE

RURAL CBR PROJECT Faridabad District, Haryana

SCHOOL of REHABILITATION SCIENCES (SRS)

- TRAINING AND RESEARCH -

APEX LEVEL ACTIVITIES

PROFESSIONAL NETWORKING CELL

LEGISLATION and ADVOCACY

GROUP on AWARENESS RAISING and PUBLICITY

INTERNAL ORGANISATIONAL ACTIVITIES

HUMAN RESOURCE DEVELOPMENT

MATERIAL RESOURCE DEVELOPMENT

ADMINISTRATION
CEREBRAL PALSY

Cerebral palsy is a physical condition affecting posture and movement. It is not contagious – it starts between pregnancy and early childhood, because part of the brain is injured or fails to develop.

People with cerebral palsy are often called "spastics", hence the name we gave our organization long ago. Today, we are working to reduce the use of this term, and to increase public understanding of what it means to have cerebral palsy.

People with cerebral palsy are almost always thought to be mentally retarded. This is because their movements are frequently difficult or not well coordinated, and often they have trouble articulating words clearly. This does not indicate mental retardation. To the contrary, many people with cerebral palsy have average or superior intelligence inside a body which doesn't cooperate easily.

There are 2.5 million persons with cerebral palsy in India today, and approximately 20,000 in Delhi and its surroundings. A very small fraction of these people have access to the services which can make the difference between an unfulfilled or a meaningful life.
SSNI OVERVIEW
A Summary of Our Activities

People with multi-disability, cerebral palsy in particular, and other neuromuscular disabilities are the focus for SSNI's work. In our rural CBR project, we work with people with hearing and orthopaedic disabilities as well. We work with families, trainees, volunteers, professionals, NGOs, governmental organisations, and the community-at-large.

A BRIEF HISTORY of SSNI

The extreme shortage of basic services for people in India with neuromuscular disabilities like cerebral palsy (CP) prompted a few women, inspired by the work of the Spastics Society in Bombay, to start a similar society in northern India (SSNI) in 1978. Their idea was to develop varied service delivery systems in rural and urban areas. These could be used, they thought, as demonstration centres for replication and extension to other parts of India. A training school was envisaged in order to facilitate this dream.

They began with a day centre in a 3 bedroom house in the Safdarjung area of Delhi for 12 children with disabilities. In 1981, they decided to reach out to rural people with disabilities, and the first rural rehabilitation centre to work across different types of disability was born at Dayalpur, Haryana. By 1984, the premises at the Delhi centre were crowded with expanding projects and activities, and SSNI began constructing the 56,000 sq. ft. building in Hauz Khas which we have been occupying incrementally over the years, and which was completed in March of 1995.

Today, as the regional centre for people with cerebral palsy and other disabilities in northern India, SSNI provides ongoing developmental and support services to over 1000 disabled persons and their families in rural and urban settings. We also do training, networking and advocacy with many organisations. Families come from neighbouring states; and trainees and professionals come from all over India for clinics and courses.

Therapeutic exercise is best when it can have an element of play. Here, Dinesh Gupta is getting his therapy this way during a gross motor session at SSNI's first CSE in the Safdarjung area of South Delhi.
DIREC T SERVICES

CENTRE for SPECIAL EDUCATION (CSE)

The Centre for Special Education educates children to their academic and personal potential, using intensive technical inputs to maximize the quality of their lives. When possible, this includes achieving postgraduate and professional qualifications. Education is not only academic in the CSE. It also includes therapy, and personal, social and spiritual values development. Students are taught to know and advocate for their rights, and to take responsibility for themselves and others.

HOME MANAGEMENT PROJECT (HM)

In the Home Management Project, parents/caregivers are trained in all aspects of rehabilitation for their child with disability. Staff assesses children’s needs and develops individual programmes for them and their families. These programmes include therapeutic exercises, positioning, communication and special education techniques, and counselling. Orthotic and postural aids are designed and provided when needed. Similar services are offered for outstation families who attend a clinic (held monthly) for one week. The families come to the centre again in 2-3 months for follow-up. Accommodation is provided for some of the families in the RORU (Rehabilitation Outstation Residential Unit) at the centre.

RURAL COMMUNITY BASED REHABILITATION (CBR) PROJECT

All of SSNI’s activities are carried out at the Rural CBR Project, which covers 35 villages in Faridabad district, Haryana. It works to increase the community’s understanding about disability and participation in activities to prevent disability; and it provides services as needed. The project trains people from the community to become rural rehabilitators and village volunteers. They liaise with existing local medical and health services, and operate their own rehabilitation centre and integrated education programme. The local panchayat and community actively work with us to run the project, and have donated 2 acres of land for the projects’ use.

Parents at the Rural CBR Project in Daryapur learn skills to handle their child’s disability, and to become rehabilitators in their own homes. Here, parents are preparing for a 3 module interactive workshop on cerebral palsy, polio, and mobility during the first few years of the projects’ work in the early 1980’s.
VISHWAKARMA WORK TRAINING CENTRE (VWTC)

The Vishwakarma Work Training Centre works with young adults with multi-disabilities to achieve their maximum potential in physical independence, communication skills, work, and social and personal development, for a satisfying quality of life. The instructors assist with locating and obtaining work in the open market, in sheltered workshops, at home, or in self employment. VWTC runs its own training-cum-production centre and sheltered workshop, through which adults with even severe disabilities can earn. Personal development is an important focus of the centre. Activities include group counselling and guided discussions for the participants, their parents and staff to develop deeper understanding of one another.

Projects Linked with Each of the Direct Services:

RESOURCE CENTRE

In our Resource Centre, we design, manufacture, adapt and evaluate low cost, custom-made furniture and aids. Rural CBR staff are being trained by Delhi based technicians and carpenters for similar work in villages. We have had guidance and linkages with the best technical and research based institutions in India and abroad.

INTEGRATION CELL

The Integration Cell aims to coordinate and facilitate integration for children and trainees from all of SSNl's direct service projects. We work for integration into mainstream schools and employment, and recreation and social activities at home and in the community at large.

Working with people in their own homes helps us to understand the realities of life and its problems for our students and families. Home visits are a part of all the direct services projects. Here, a multi-purpose rehabilitation worker from the VWTC interprets for Raju Saraf, who points to letters and numbers on a "communication board" in order to speak to staff during a home visit. Raju's mother and sister-in-law, listening here, are also able to use the board for communicating with Raju.
APEX ACTIVITIES

SCHOOL of REHABILITATION SCIENCES

Training

The School of Rehabilitation Sciences designs and runs training programmes and conducts ongoing research to increase SSNI’s effectiveness, and to share its knowledge and experience as broadly as possible in India. Trainees and professionals from all over the country, and staff, parents and volunteers from each of our project areas participate in training and research.

Trainees/lecturers for the courses include working professionals, although the core staff are from SSNI itself. Trainees practice new skills and knowledge immediately by observing and working with students and trainees in SSNI’s direct service projects. Admission criteria for postgraduate courses are changing to allow for trainees with a wide range of educational and experiential backgrounds to attend. Practical and functional skills are taught in the field, in the CSE school, and urban and rural communities.

Scholarships and hostel facilities allow us to train people from many Indian states where there is little present expertise, so they may return to pioneer services and training in their own areas.

Research

Data bases are maintained by all projects, and action-based clinical and educational research is on going in the areas of assessment for better prediction of rehabilitation and surgical outcomes, impact evaluation, rehabilitation techniques, and the development of innovative aids and appliances.

LEGISLATION and ADVOCACY

The Legislation and Advocacy Cell was created in 1995 to work towards the security and equalisation of opportunity for people with disabilities all over India. Staff and students are participating at a national level in disability rights and self advocacy work. Senior management staff are contributing to policy analysis, planning, advocacy and legislative lobbying with governmental and non-governmental agencies, at a national and international level.

PROFESSIONAL NETWORKING

The Professional Networking Cell was organized in 1995 for ongoing information dissemination, consultation, and advisory activities which have evolved in each project as our experience has grown. This includes developing mutual partnerships with outside groups and individuals, including professionals and trainees and the public at large.

The Legislation and Advocacy Cell and the Professional Networking Cell are being joined during 1995/96 to create the Networking, Information Dissemination, Disability Development and Rights Advocacy (NIDDRA) project.

AWARENESS RAISING and PUBLICITY

The Group on Awareness Raising and Publicity (GARP) was also formally organized during 1995, with the goals of 1) developing awareness about the rights and abilities of people with disabilities for equal access; and 2) creating media and communication tools to educate the public about SSNI. Each week, SSNI holds an “open day” for school groups, college students, visitors from our neighbourhood and potential donors to walk in for a guided orientation. Staff take turns guiding the tours.

A group of SSNI staff from the Rural CBR Project, a parent, and a consultant with a disability himself, travelled to 4 CBR projects in Africa in 1995, to learn from others’ experiences and to understand the commonalities and differences which define their CBR work. Here, at the Kilwezi CBR Programme in Kenya, a group of parents get together once a week to make bags as an income generating project. They originally began this work as a result of their poverty, but have gone beyond producing income as a single goal. Now they begin their day with a play group for their children, who have a variety of disabilities. Also, an essential support group has emerged for them all.
INTERNAL ORGANISATIONAL ACTIVITIES

HUMAN RESOURCE DEVELOPMENT (HRD)

Human resource development at SSNI means developing each person’s full potential. It has involved developing new management systems, empowering staff and students/trainees to participate in decision making, and offering education and training for all staff. It includes developing the potential of parents as rehabilitators and conducting training programmes for volunteers. Staff members travel to projects around India on CBR study tours, learn through regular in-service workshops, and several staff are receiving postgraduate training in the UK to enhance their skills.

MATERIAL RESOURCE DEVELOPMENT

SSNI raises funds by holding a major cultural event each spring, selling greeting cards made by the children, and by writing grants. We are now also working to build up a corpus fund to provide security and sustainability for our projects.

ADMINISTRATION

Administration provides the central infrastructure for SSNI’s service delivery projects and all its operations.

VWTC trainees from the Product Manufacturing Unit make the SSNI Delhi Centre’s reception area lively on their monthly payday. Mr. Muthu Subramaniam, Jr. Accounts Officer, has his desk centrally located here for handling cash accounts. Mr. Subramaniam has CP himself. He was the staff member some of the VWTC trainees chose to be their supervisor for their first independent trip out of station, to Haridwar, in 1994.
A critical process of self-evaluation and deep change began for SSNI during 1990, with a series of brainstorming meetings by each project, and then by all projects with ODA advisors. We began asking ourselves how effective we were from the point of view of our students, trainees and families. We began studying new concepts in community based rehabilitation (CBR) and began thinking about how to apply these in our urban centre-based work, as well as in the rural CBR project.

Ultimately, four key areas emerged as crucial for focusing and improving our work: moving into the community to work; increasing work with people living in poverty; working for quality of life and personal empowerment, and re-structuring administrative systems to decentralise, and share responsibility and decision making more equally between ourselves, and with our students/trainees and families.

VISION/MISSION RETREAT and VALUES DEVELOPMENT

At Anandgram in January 1994 we gathered together for a retreat, to give us a chance for reflection. Ideas about empowerment and quality of life which have been forming for the past few years transformed into concrete decisions to guide us in our work. More than a year later, we are continuing to actively put these decisions into practice.

During the retreat SSNI staff clarified our values and principles and designed a new statement of our mission (see inside front and back covers).

Principles from community based rehabilitation were taken as a cross-cutting foundation for our work in all service areas. Concepts like equality and empowerment are now being integrated into all projects, at every level of work. This gives us a widening perspective of our roles - seeing ourselves not as professionals with narrowly defined specialist skills, but as generalist rehabilitators. It leads us to think of a child as a whole person, not only as a student or trainee with educational or emotional or physical or family needs. An emphasis on promoting quality of life has expanded in all of SSNI’s activities.

VALEDICTORY FUNCTION, February 1994. The Dalai Lama was with us for our Valedictory function in February 1994, for graduates of the TTC and BDT courses in the School for Rehabilitation Sciences. He reminded us to think of our strengths, and stressed the importance of believing in ourselves. He inspired us all with the gentleness and deep compassion he embodies, and his spirit lives with us. Prior to the event, the children learned about the Tibetan cause, Buddhism and its values, and they learned a mantra. The children were so moved by being with the Dalai Lama, that they organized a project to collect money for the Tibetan refugee camps in northern India.
RE-STRUCTURING of SSNI

In December of 1994, Dr. Brian O'Toole, a renowned CBR educator and writer from Guyana, spent two weeks training and evaluating SSNI for the ODA. He helped us to see our work with a new perspective, and confirm the direction of change which we had begun more than a year before. We looked at the torrent of work beyond our formal roles and duties which had flooded all of us - at the same time as it excited and stimulated us to do even more.

Then during a week long workshop in January 1995, Mr. Ricky Surle, an international management consultant, helped us re-conceptualize our work. The following areas were identified as “emerging” projects, to legitimize and budget the time we spend on them, and to identify coordinators for each area:
- Legislation and Advocacy
- Professional Networking
- Awareness Raising and Publicity
- Integration
- Human Resource Development

Restructuring has allowed us to develop as an apex body for NGOs, governmental agencies and individuals working with/for people with disabilities in India and other countries.

With increased organisation comes the sense that although our scope of work is increasing, it is manageable, and this gives us renewed energy. The rewarding contacts and inputs from others now working with us from outside our walls also gives us a sense that we can successfully challenge ourselves with new roles and areas of work.

Management at SSNI has re-oriented to a bottom-up style, using consensus decision making whenever possible. Ownership and responsibility for SSNI are taken not only by identified leaders and administrators, but by a large number of staff.

WORKING for EMPOWERMENT

During the year, we began to listen more carefully to students and trainees, and to actively involve them and other people with disabilities in all levels of decision making. This has resulted in what visitors and evaluators report is a respectful and participatory feel to the organisation. More importantly, the students and trainees are taking more decisions and responsibility for themselves, like planning and conducting school assemblies, and taking field trips independently, trying out self-employment, writing letters to make buildings accessible, and lobbying for civil rights.

MOVING into the COMMUNITY

We have begun to re-orient to working outside the centre, with people in the community; and to focus more on people who live in poverty and in urban slums. Staff are re-training and networking with others more experienced in working in the urban slums to build up confidence and skills.

"Moving into the community" is interpreted independently by each direct-service group within SSNI, but for all it means more work to serve people with the least resources and most need.

Mithun rarely left his house or showed interest in outside activities, until the Rural CBR Project staff created and adapted this tricycle for him, with supports for his back and protective boxes for his feet.
DIRECT SERVICES

CENTRE for SPECIAL EDUCATION (CSE)

HOME MANAGEMENT PROJECT (HM)

RURAL CBR PROJECT, FARIDABAD DISTRICT, HARYANA

VISHWAKARMA WORK TRAINING CENTRE (VWTC)

RESOURCE CENTRE

INTEGRATION CELL

Hitesh Wallia struggled at first in the CSE to use his hands, like other children, but always had difficulty due to spasticity. Then, during a home visit, his teacher and speech therapist noticed him doing a lot with his feet. Now, Hitesh uses his feet and toes at school, too. It has opened up new activities and made others easier for him.
CENTRE for SPECIAL EDUCATION (CSE)

BRIEF HISTORY

The CSE opened in 1978 with 12 students and 8 staff. There were 77 students and 27 staff in our daily programme as of July, 1995. CSE is expanding its scope in concept and in numbers. This growth represents an effort to serve more children; and also allows us to continue using the school as a learning ground for SRS trainees, and for designing new appropriate technologies, including assistive aids and appliances. We are working to ensure that the children we reach are those who have no access to alternatives in the mainstream, and we are increasing the proportion of children from economically poor families in our school.

CENTRE for SPECIAL EDUCATION

- Primary Section
  - (22 children) Preschool group, Nursery and pre-primary group, Grades 1 and 2.

- Academic Section
  - (13 children) National Open School, CBSE.

- Functional Abilities
  - (42 children) Pre-junior group, Junior group, Pre-vocational training group, Severe multi-disability group.

SERVICES PROVIDED

- Academics
  - Special education and therapy techniques, like Aural Reading, Conductive Education, and Augmentative Communication
  - Enriched learning environment, small classes
  - Individualized programming and attention
  - Integration into mainstream schools and colleges
  - In-depth preparation for Class X Board examination (CBSE and National Open School)

- Therapy
  - Physical, occupational and speech therapies

- Psychological Support
  - Counselling

- Personal and Spiritual Development
  - Leisure time activities, hobbies, outings and field trips
  - Drama, music, painting and crafts classes
  - Spiritual values curriculum and groups

- Psychological Support
  - Parent and family guidance, counselling, and support, with lectures, videos, films, spirituality sessions

- Health Care
  - Medical management and referrals for corrective surgeries with follow-up

- Staff training

The CSE school has small classes to allow for individualized special education for the children. Sunil Sajwan, Mitul Mehra and Kusum Kumari (left to right, pictured here with their teacher Mrs. Kumar) are academic students in the CSE's Primary Section.
Amrit Pal Singh did not run out to play like other ten year old children. He sat at home all day and did not go to school. His father, a skilled technician working in Delhi at that time, had given up all hope that his son would ever be "normal." Amrit Pal had very little control over his body and was totally dependent on others for moving around. He had severe cerebral palsy. "I thought I was a minority of one," wrote Amrit Pal later, "until I heard that a school had been opened by the Spastics Society especially for children like me."

Today, Amrit Pal is one of a group of accomplished young adults with cerebral palsy, who are the first generation of visible leaders for people with multiple disabilities. They are writing and speaking publicly, and actively participate in government policymaking committees.

Amrit Pal was one of the first students at the Spastics Society school in 1978. He completed classes one through twelve in nine years, a remarkable achievement by any standard. After taking the All India CBSE 12th Board Exams, he went on to successfully complete an honors course in mathematics at Venkateshwara College, part of the prestigious Delhi University. He studied computer programming at NIIT, and opened a computer consulting business this year, which he runs from his own independent apartment. Amrit Pal is living life in the mainstream. It is not always easy, but he says, "So many things can and do go wrong, but I'm the only one who's normal. Everyone in my family worries, I mean, worrying about the problem doesn't solve it."

Amrit Pal's love of people and humor are important factors in his success so far. "One thing that separates me from some of my other friends at SSNI is that I never let myself feel isolated," he says. "In fact, I like the company of so many people. So I give advice to others, that let people look at you, but don't let it bother you. They've already made up an opinion, so why worry?" And he adds, "If I have a good sense of humor, I got it from Vinita at SSNI. (Vinita is a lead teacher, working at SSNI for the last 17 years.) She's so funny. Even when other people are nearly crying, I can crack a joke, and I got that from her."

Amrit Pal's accomplishments have meant hard work. It took many difficult years to learn just to walk and move independently using crutches. He then studied nonstop at the Spastics Society school and with tutors to pass his 9th standard exams, having not concentrated on academics earlier. "One thing I got from SSNI," he says now, "was that you should be prepared to face the consequences of everything you do. To be ready for everything. It hasn't all been a picnic, but they paved the way for me. If we did something wrong, we were punished like anyone would be. It didn't feel good, but that experience helped me. Now, when I feel like going home and if I can't go there, then the second place I want to go is to Spastics Society of Northern India. It's like that because I spent most of my time there. I saw the new building coming up brick by brick. It sounds sentimental, but it's true. There is a brick I laid there in the basement - in the foundation. So one of the bricks belongs to me there."
HOME MANAGEMENT

BRIEF HISTORY

The Home Management Programme opened in 1980 with 50 children and their families and 6 staff. As of July 1995, 647 children and families were served by the project yearly, by 13 staff. It is taking its services to the homes of children living in poverty; discovering and utilizing the networks which already exist in their neighbourhoods, or developing new networks to access the rehabilitation services and access to school, work and social life which they may need.

Home Management trains parents to move away from dependency on institutions and professionals.

SERVICES AVAILABLE

Assessment
Early detection, diagnosis

Therapy
Infant stimulation
Physical, occupational and speech therapy
Behaviour modification

Health Care
Sponsorship for medicines, aids and other needs

Home Visits
Assessment, therapy, education, counselling, resources
Adaptations for the home

Education
Special education
Supportive educational programming for children integrated into regular schools
Deaf education for children with CP and hearing impairment
Functional literacy and numeracy
Regular pre-school education
Integration into regular schools/work places
Educational equipment library

Psychological Support
Individual counselling
Parent support groups
Shelter, suicide prevention

Personal and Spiritual Development
Outings and recreational experiences
Monthly discussions and singing

Availing of Government Concessions and Facilities

HOME MANAGEMENT PROGRAMME

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<td>Assessment of child, fortnightly services</td>
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<td>Home visits, assessments, therapy, counselling and referrals</td>
<td>Respite, therapy &amp; educational activities Volunteer training</td>
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A therapist in the Home Management Project counsels the parents of one of the children. Counselling is a central element of all projects at SSNI, for solving problems and helping to alleviate some of the pain each person with a disability and each family experiences by listening, understanding, accepting, and offering resources and guidance as needed.
Profile: RAMESH ARORA

“My life is just like a movie picture. I’ve seen so much in life.” When Ramesh Arora’s second son was born with cerebral palsy and mental retardation like her first also had, her world was shattered. She remembers, “At first, I could not accept it. It took me a long time, about 8 or 10 years, to accept my reality and slowly change myself. I came to it that nothing else will change, so why to be always unhappy? Still, at times even now I feel very low from the physical work and the financial problems.” Today, Ramesh supports the family with a small tailoring business she runs from the front of her tiny one-room house in Pahar Ganj near the New Delhi railway station. She has become a leader and an important resource for other parents at SSNI who are not able to accept the prospect of a lifetime with a child who has a disability. Her natural resilience, and the cheerful, determined high spirits which one takes for granted on meeting her, were not always apparent, according to the staff who are close to her at SSNI. Especially not during the early painful years of adjusting to life with 2 sons with severe disabilities and a husband who also has limited abilities.

Summit, pictured here, is now 15 years old and is totally dependent, physically and mentally, for all activities of his life. He is not able to respond to people or communicate. Nine year old Vickey has lived with Ramesh’s mother in their village home 200 km from Delhi, since six months ago. He is free now to spend the boundless energy he once used for removing and throwing objects in the small space of their home in a more enjoyable way for him and less disruptive way for his family. Ramesh and her husband miss him, as he is at least able to respond to them. She says, “I’m happy with Vickey when he smiles and interacts, and now he can drink by himself and can sometimes tell us about needing the toilet.” But with him away, and because her husband has begun to take care of Summit, she is finally able to earn some money at her tailoring and embroidery business. And Vickey is said to be happy in his new rural home.

Ramesh first learned about the Spastics Society in 1983 from a fellow passenger on a bus to Agra who had a daughter attending the school. She began taking 3 year old Summit to the school, an hour away by bus, for therapies and to learn ways to handle his basic daily needs for the best care possible at home. She had individual counselling and attended parents’ groups at SSNI, for developing coping skills. Today she continues to attend monthly parents’ meetings, talks on spirituality and bhajans. And she maintains contact by phone weekly with Sanyukta, a special educator for the Home Management programme, who also makes occasional home visits. She goes for counselling from a local doctor whom she says helps her to accept fate and use her faith in God for strength. Writing in her diary daily, singing, and resuming stitching work have also played a big part in her remarkable ability to adapt to and face her life with positive vigour, becoming a role model for other parents.

She says, “I want to live for myself also, not only for the family. Someone told me you have to live for yourself, even if it’s just 2 hours a week.” With this determination, she lives for her family pretty much the rest of the time.

As she has adjusted to the realities of her children’s needs, Ramesh has developed some positive ways to think about them. She says, “If you have a normal child, you have more expenses. But these children take more of your time. People with normal children are not always happy either. They are always trying to find more for them, so there’s not much difference. The main difference is that the needs of normal children are too many. Whereas our children will not ask for anything. You don’t have to worry about their homework and schoolwork.”
RURAL COMMUNITY BASED REHABILITATION PROJECT

BRIEF HISTORY
The Rural Community Based Rehabilitation (CBR) Project began in 1981 in Faridabad district, Haryana with 9 children and their families, 5 part-time local staff and 4 Delhi-based professional staff. It was the first rural rehabilitation project in India to work with people across disability, including cerebral palsy, polio and other orthopaedic disabilities, mental retardation and hearing disability. As of July 1995, there were 282 children or young adults and their families participating in the project annually. Two part-time local staff, 13 rural rehabilitators, 6 volunteers and 8 Delhi-based professional staff work for the project. The project centre is located in Dayalpur, with 2 subcentres in Tigaon village and Ballabgarh. Both semi-urban and rural communities are included in the projects’ work.

After 14 years of work, the rural centre is preparing to become more self-sufficient and less dependent on urban staff for technical skills, training, and support for rural staff and volunteers. This change requires slow and careful encouragement and preparation. Rural staff are expanding their skills and their understanding of the broader aspects of their work, beyond individual jobs. As their vision grows, they are taking increasing initiative. Urban staff will continue to be a resource for the project, but in smaller numbers than in the past, and in a more consultative role.

RURAL CBR PROJECT

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The Rural CBR Project provides integrated rehabilitation, health, and development services through the work of trained rural rehabilitators and village volunteers, parents, and the community-at-large. Here, a group of parents are learning about mobility aids to help their children move and walk. A father is explaining to a grandmother how the child’s hands need to be placed to properly grip the bar on a walker.
Profile: RAMESH CHAND

Ramesh Chand was working at masonry and farming jobs when a friend told him about SSNI’s Rural Rehabilitation Project’s training programme for village volunteers 14 years ago. Ramesh had always wanted to do “Seva”, and he took the training, which was geared for villagers with no more than 8th standard level education, like himself. He began work by bringing a child from a neighbouring village to the project’s centre in Dayalpur for rehabilitation therapy, and over the years has now become a key staff member. He makes home visits three days each week, assessing children’s needs, teaching parents simple therapeutic exercises and positioning for their children, and providing aids and appliances.

A typical day for Ramesh begins with work in the fields along with his wife, collecting fodder for their buffaloes. He helps bathe and get his 3 children ready for school, and then rides 15 km on his bicycle to the Dayalpur Centre. In addition to his home visits in several villages, he handles all orthotics needs for the project. Until Ramesh took responsibility for aids and appliances, the project had to find technical experts or professional therapists for wheelchair repairs. Ramesh developed connections with local bicycle repair shops. Now repairs are done locally or by Ramesh himself.

On Fridays, Ramesh makes the 50 km trip to Delhi for training in orthotics to upgrade his skills. He can now repair calipers on his own and runs a monthly orthotics training clinic for co-workers with a technician from Delhi, held in the project’s Ballabhgarh sub-centre.

Once a week, Ramesh goes to Tigaon village - one of the project’s two subcentres - to get together with other village volunteers for problem solving sessions and mutual support.

Home visits provide a wealth of information to the rehabilitation workers who need to train parents and work with children in a way that makes sense, given the reality of their home situations. Here, Ramesh Chand demonstrates for Dipak Madan and his mother how to use special cushions in Dipak’s wheelchair. The cushions will help him sit properly, preventing back and limb deformities which can easily occur without such aids.
VISHWAKARMA WORK TRAINING CENTRE

BRIEF HISTORY

In 1985, a pre-vocational and vocational unit was started by the CSE for young adults with the potential for work; and in 1986 an Independent Sheltered Workshop was launched with 22 trainees. The VWTC has evolved from these origins to become a training, work production, placement and income generating project. As of July 1995, there were 10 staff. Fifty-four trainees and employed clients, ages 16 to 35 and with a wide range of physical, neurological and mental disabilities, were participating in VWTC’s projects.

Trainees spend 2 years at the VWTC, during which they receive specific training for appropriate work, suited to their abilities and interests. A goal is for the trainees to become independent in at least one vocational skill. The project is progressively increasing trainees’ exposure to real life work situations and developing work stations to simulate actual jobs. Beyond work, the project is re-focusing on “quality of life”, to include other forms of activity besides paid work, as goals for a satisfying life.

OTHER SERVICES PROVIDED

◆ Therapy
  Physical and occupational therapy
  Speech therapy, and training in functional communication skills
  Postural, functional and vocational aids

◆ Training
  Monthly in-services for all staff
  Parent training

◆ Medical Care
  Medical and surgical management and referrals

◆ Psychological Support
  Individual and group counselling
  Suicide prevention
  Caregiver support

◆ Personal Development
  Self esteem, hygiene, domestic skills, hobbies
  Interpersonal skills development
  Parent training, guidance, counselling
  Spiritual coping

Sushil Thakur creates hand block-printed stationery, bags and other paper products at the VWTC’s Product Manufacturing Unit. Sushil is one of VWTC’s trainees who is also earning a salary for his block printing work.
Profile: RAJU SARAF

As a young child, Raju would let his sister know when he saw other children playing in the dust outside, and would make her put him there, kicking up the dust for him, too.

When he learned about the Spastics Society school seventeen years ago, Raju applied but was not accepted initially, due to the severity of his disability from cerebral palsy, and the fact that he did not fit easily into the limited programmes available in the early days of SSNI. So he staged a dharna in front of the school, refusing to eat until he was accepted by the school. It worked.

Four years ago, as a trainee in the Work Training Centre at SSNI, Raju was learning block printing and didn’t like it. He decided he would not be able to have his own business that way, and he came up with the idea of taking a tray filled with novelty items (attached to his wheelchair) to a nearby outdoor market to try his hand at having a shop. Despite the misgivings of even his instructors, Raju insisted, and staff from SSNI accompanied him daily at first to sell his wares. “My family didn’t like it, there was a lot of opposition,” Raju says. His mother remembers, “We were afraid that people might trouble him, or a cow or buffalo might eat his stuff.”

Raju is dependent on other people for mobility, and communicates by pointing on a board which displays letters and numbers, as he is unable to speak. Experienced staff at SSNI had thought that a sheltered workshop would be the highest goal for Raju. But he enjoyed selling in the marketplace, and his happiness and beginning signs of success convinced his family and instructors to continue to support his dream.

Today, Raju has a small shop which he runs in the shopping centre across from his home. This did not come easily. In the first location he tried, the shopkeepers effectively refused him a place by thinking up a constant stream of approvals and official government papers for him to acquire. The shop he finally set up has been possible because of a friendly shopkeeper who agreed to share his space with Raju, providing him with security and occasional assistance.

Raju’s cheerful nature and brilliant smile are part of his success. His mother says “He’s a lucky guy. Everyone loves him.” And Shalini Chopra, co-ordinator of SSNI’s Work Training Centre, says “I’ve benefited a lot from Raju. He is the one who made me appreciate motivation as an essential part of my list of criteria for successful work for our trainees.”
RESOURCES CENTRE

One of the critical needs of a person with disability is to have appropriate aids for better physical functioning. Specially designed aids to improve posture and hand function greatly increases confidence and self-esteem for people with disabilities. Many aids they need are not available in the market. Those that are commercially available, such as walkers or splints are sold at very high prices. Because each aid also has to be suited to the individual person’s needs, SSNI felt a crucial need to set up their own designing and manufacturing Centre.

The SSNI Resource Centre began work in 1985 with 1 carpenter. It is currently staffed by 3 carpenters and relies on its own carpentry unit for making wooden postural aids. It works in collaboration with two orthotists, Naeraj Saxena and V. Gulati, for aids made from other materials. The two units together produce urgently needed postural, mobility, daily living and other orthotic aids which are either loaned out, sold on payment of extended installments, or given free, depending on the financial capability of the client.

A special benefit of this service is that the aid is measured, fitted, and adjusted at our Centre’s premises. This allows for close supervision by our trained therapists, as well as convenience for our students and trainees, who because of their physical condition cannot easily travel to commercial centres for these services.

Rural rehabilitation staff in the CBR project at Dayalpur are replicating this work following training at SSNI’s Delhi centre.

These crutches are made of bamboo, an example of using locally available resources and concepts of “appropriate technology” to provide low cost aids and assistive devices for people with disabilities. The carpenter comes from the Dayalpur area of the Rural CBR Project, and he volunteered to make these crutches.

One of SSNI’s carpenters measures the dimensions of a chair he and a therapist are designing together for Sachin Sajwan, a child in the Home Management Project. The chair they make will help Sachin to sit upright in a posture which protects his body and is more comfortable for him than ordinary chairs.
INNOVATIONS

Problem solving and innovation are the cornerstones of all rehabilitation, and the basis for much of our work. Staff make use of the idea that a mirror meaning of crisis is opportunity, and they try to approach problems as opportunities for change and innovation.

The efforts staff have made to work with parents as equal partners instead of as “clients” has led to identifying and strengthening parents’ skills for rehabilitation work with their own children; and for their running workshops, setting up support groups, counselling, handling emergencies, and making therapeutic and educational aids and assistive devices for the children. A wide range of volunteers, including some of the children’s parents, complement the work of professional staff for providing therapy and teaching in all our direct service projects.

Staff in the Centre for Special Education adapt and design original assessment schedules, checklists and questionnaires to evaluate the children’s and families’ potential to benefit from rehabilitation.

Curricula for the children in the CSE include not only academic activities, but also age-related skills, human and spiritual values, and leisure time and social activities, to make living a full, dignified and enjoyable life more possible.

The Home Management project has created a multi-faceted support system for stressed families and people with disabilities. It includes a network of home visiting volunteers, community day (“respite”) centres, parent support groups, and social occasions. Participants in all of SSNLI’s projects are included in this network of support.

Home Management’s outstation project, with its Residential Outstation Rehabilitation Unit ("RORU"), has been an answer to the needs of families from parts of India with no facilities for children with cerebral palsy and other neuromuscular disorders. These families live at the Delhi centre with their children for a clinic held for one week each month, participating in assessment, training, counselling, and obtaining therapeutic aids and assistive devices.

The Rural Rehabilitation Project at Dayalpur was the first CBR project to work with people with a variety of disabilities in India. It started the first basic training in India for illiterate and semi-literate people to become village rehabilitation volunteers, and intermediate level training for people with 8th to 10th standard education to become rural rehabilitators. With UNICEF’s help, we made "Kamla", a film about this training as seen through the experience of one of our rural rehabilitators.

In the Vishvakarma Work Training Centre, counselling has been taken in new directions by the formation of groups for trainees and their parents, facilitating unprecedented open discussions about the personal and intimate issues people with severe and multiple disabilities face in their daily lives at home.

The Resource Centre designs custom-made mobility aids, orthotic devices, and special furniture, experimenting regularly to find therapeutic solutions for children who fit no mould.

The School of Rehabilitation Sciences created a one year "Basic Developmental Therapy" (BDT) training course, the first of its kind, in 1988. This course prepares skilled physical/occupational therapists, and is an alternative to longer professional training programmes, 75-90% of whose graduates leave India for jobs overseas.

Kamla, a rural rehabilitator as well as the parent of a young man with polio, is demonstrating here how to fit a caliper properly for walking. She is teaching Phoolwati, a woman from Tigaon village who is not able to read, but who would in time become an able village volunteer for the project.
INTEGRATION CELL

An Integration Cell was formed in 1995 to organize and increase mainstreaming for people with disabilities. A primary goal of integration is to facilitate equal participation in activities at home, in school, at work and in the community, to the extent possible. While staff in each project already do the work of integration, this cell provides for a coordinated system for collecting information, and for expanding our efforts.

During her ODA monitoring visit to SSNI in May 1995, Sue Stubbs (Overseas Disability Advisor for Save the Children Fund), made the critical point that integration does not mean trying to be the same as others. A child with disability will grow up as a disabled adult, and needs to feel positive about that, rather than pretending differently. She needs to know that other people in society do discriminate, but that it is not her fault.

We have recently integrated young children into regular schools, and we are also working with children who were already integrated prior to their admission to SSNI. These children have not had the years of preparation (for example, in toileting skills or independent mobility, like climbing stairs) which our older students have had prior to integration. There are many new problems to solve as well as great potential for the younger children.

In an ongoing analysis of the progress of children integrated into regular schools during 1994-95, we found that 8 of 25 children were asked to leave at the middle school level. These were the children who had been integrated prior to admission at SSNI. Active follow-up is teaching us how to solve such problems and make realistic predictions for success.

The CSE teachers who initiate integration for children from SSNI into regular schools do enormous behind-the-scenes work with principals, teachers, parents and the children themselves in order to make integration successful.

Samuel Mani has managed to make friends at St. Mary's School in Delhi, and to get beyond the stigma a wheelchair can easily create.
Hemant Khemani was the first child born to his parents after 11 years of marriage. When he first came to the Spastics Society school in 1983, he was 4 years old, and was not able to walk. He had difficulty crawling, and had such severe perceptual problems that later the units and tens columns in a simple addition problem would merge into a confused pool of numbers for him.

Hemant says, “For a spastic child, family is the main driving force. My mother has given her whole life to me. I’m lucky to have been born into such a family that gave me so much support.” With his family’s dedication and the 10 years he spent in SSNI’s CSE programme, 3 surgeries for contractures and one surgery for a severe squint, Hemant is now attending one of the best intermediate schools in Delhi. He walks with crutches, is able to navigate the stairs independently to his first floor classroom at St. Mary’s School, and has perfected his wheelchair skills for longer distances. He has achieved enormous success, beyond others’ expectations. Last year, he passed the All India CBSE Class 10 exams in 9 subjects (with no concessions) with 71% marks. The exams are especially difficult for students like Hemant, who cannot write due to their perceptual and fine motor coordination problems. They have to rely on others to write their exams for them. This means they must dictate all answers, and be able to verbally communicate to another person how to correctly mark down even mathematical drawings and equations.

Hemant says, “People’s attitudes are not all that advanced. There is still a line which divides spastics from normal children. I don’t say we haven’t changed, but we have to go a long way. Spastics should from the beginning be in a normal environment. I joined St. Mary’s in the 11th. It gave me much less time to adjust myself. And St. Mary’s is one of the only organisations that has accepted spastic children.”

“Spastics as such is a brand,” he says. “You can remove it by your determination and hard work, but it requires a lot of hard work. If you can prove to society that you can remove this brand and you are able, then society will accept you. We have to do it. We have to take everything as a challenge.”
SSNI as an APEX BODY

In 1992, the Overseas Development Agency worked with SSNI to define objectives for the 3 year period of ODA’s grant to SSNI. An “enhanced role for SSNI as an apex institution for research, training and policy on cerebral palsy in India” was one of the primary objectives, and has been a focus for increasing activity during the period the grant covers.

SSNI is now focusing on the “macro” issues of disability, in addition to our ongoing work with individuals. This takes the form of training and research, policy review, legislative action, and mobilizing other NGOs towards accepting a disability focus as a mandate. We have included students from all over India in our courses, and we are developing a training of trainers approach for wider impact.

SSNI is networking across India with people who have disabilities as mutual partners, with NGOs and government organisations in a rapidly expanding community concerned with achieving equal opportunities and human rights for people with disabilities.

Apex activities include projects begun during 1995, such as a Legislation and Advocacy Cell, a Professional Networking Cell, and the Group on Awareness Raising and Publicity. SSNI is beginning the development of an all encompassing project for these activities, called NIDDRA: Networking, Information Dissemination, Disability Development and Rights Advocacy.

The School for Rehabilitation Sciences plays an apex role through its training for rehabilitation professionals from a wide region in northern India, by its pioneering work in the field of training for community based rehabilitation workers, and the training materials, including videos, which it makes and shares with other schools and disability rehabilitation workers.
APEX ACTIVITIES

SCHOOL for REHABILITATION SCIENCE

LEGISLATION and ADVOCACY CELL

PROFESSIONAL NETWORKING CELL

GROUP on AWARENESS RAISING and PUBLICITY

CSE students visited Lalit Kala Akademi during the fall of 1995, to see a painting exhibit by a staff member's relative. They used this opportunity to advocate for their rights, as well. Prepared for the flight of stairs they had to "climb" to see the exhibit, staff carried the children in their wheelchairs one after another up the stairs, and then at the end of the visit, down again. The students had prepared a letter in advance and handed this over to the Deputy Director, who assured them that their request for a wheelchair ramp would not be ignored. In December, 1995 students received a letter from the Akademi stating that they are now considering plans for the ramp.
THE SCHOOL of REHABILITATION SCIENCES (SRS)

TRAINING

BRIEF HISTORY

The School of Rehabilitation Sciences opened its first formal training for special educators, a one year Teachers’ Training Course (TTC) in 1984. In 1988 the Basic Developmental Therapy Course (BDT), also a one year course, began. These courses have GOI approval, and are models for training. They integrate theory and practice and are taught by working rehabilitation and education professionals. The courses offer basic to highly advanced professional training. Given that over 75% of India’s rehabilitation graduates leave the country, training courses such as these serve a critical need.

Basic and Intermediate Training for Rural Rehabilitators

In the rural CBR project, courses are run periodically to train basic level “village rehabilitation volunteers” and intermediate level “rural rehabilitators”. Most current staff for the rural CBR project have been trained in these 2 courses.

Basic Parent and Volunteer Training

Ongoing parent training is offered throughout the year in both urban and rural projects. During 1994/95 a new one month training for volunteers was created with the Home Management project to prepare volunteer staff for community day centres associated with SSNI.

Intermediate and Advanced In-Service Training for Staff

In-service workshops and seminars are regularly conducted for staff in all projects by experienced SSNI trainers and outside professionals.

Post Graduate Training

As of July 1995, the TTC course had trained 103 special educators, and the BDT course had trained 49 developmental therapists. Many of SSNI’s current staff were trained in the early years of the courses, and can be seen today managing the school and teaching in all the SRS’s courses. At present 4 coordinators run the TTC and BDT courses, which draw experienced trainers from the community in addition to the SRS’ own staff. Both courses are recognized by the RCI.

Advanced Professional Workshops

Beyond the post-graduate TTC and BDT training, SRS also conducts advanced workshops for outside professionals on a wide range of subjects, like assessment, therapeutic techniques, problem solving skills and management.

Study Tours and Training Abroad

A series of overseas tours to Africa and South-East Asia, and training in the UK for four staff members was funded by the ODA during 1994/95. These tours have increased staff’s understanding of CBR and its practice in other parts of the world. Staff receiving training abroad are combining their studies with research based at SSNI.

SRS TRAINING

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<tr>
<td>Basic</td>
<td>Intermediate</td>
</tr>
<tr>
<td>Village volunteer training</td>
<td>Rural rehabilitator training</td>
</tr>
<tr>
<td>Apprenticeships</td>
<td>Parent training</td>
</tr>
</tbody>
</table>

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RESEARCH

"One of the greatest weaknesses of rehabilitation programmes internationally is the dearth of empirical evidence for their effectiveness." (Brian O’Toole, CBR educator/evaluator)

Research is an ongoing aspect of each of SSNI’s projects. Data bases are continuously maintained and updated by each direct service project, and information is used by staff in improving their services to benefit students and family members. SSNI’s research is action-based, and clinical in focus.

Research at SSNI is still informal in nature. As yet no large scale or comprehensive research has been done, due to a lack of resources for such work. Areas for research and development include:

- Functional outcomes of surgery, and prognosis following surgery
- Innovative aids and appliances
- Augmentative Communication tools
- Family Assessment Inventory: relating family background to the likely benefits of rehabilitation, for better predictions
- Ongoing surveys: e.g. How effective are our village rehabilitation workers?

The ODA has funded M.Sc. training in the UK in rehabilitation sciences for 3 senior staff at SSNI. One benefit of this training is that they will be able to carry out action-based research on-site at SSNI, with training and backing from a university. One senior staff member, for example, will be researching criteria for defining success in rehabilitation from the perspective of the community. She will carry out her data collection at SSNI, after completing course work in the UK during 1995/96.

Mrs. Ujjwala Shankar, therapist for the Home Management Project, instructs volunteers in SRS’ annual one-month volunteer training course. The volunteers are learning here about the therapeutic splints which are used for improving hand functioning and positioning for children with spasticity. Students like Poonam Gujral, pictured here, contribute to the course by allowing the trainees to learn from their needs and experiences.
PERSONAL and SPIRITUAL VALUES

When you talk of quality of life, you have to think about spiritual strength. "This is not religion or ritual. It is deep spirituality which helps us sort out conflicts, forgive one another and feel empowered to work. This reliance on spiritual concepts is much more effective than any form of counselling. This concept of oneness has helped us cut across all barriers of religion, caste and social hierarchy."

(Gloria Burrett, SSNI Director)

It was Tuesday at 1:30 pm, and all the staff at SSNI were busy finishing work early to be ready for a Teacher's Day party. Suddenly, quietly, word passed around that our communications consultant, Pradip Singh had lost his balance and fallen on some mossy bricks. His tibia was badly broken, jutting out at right angles to the rest of his leg. Pradip has a severe disability from infantile rheumatoid arthritis and has developed a remarkable degree of mobility, using crutches, despite enormous stiffness and pain from his arthritis. This break was terrifying to him and to the rest of us.

After making all arrangements for pain killers and safe transport for Pradip to a known hospital, the staff gathered in the room where the party was to be held. Instead of beginning festivities, all sat together and soberly shared their reactions, concerns and discussed whether or not to hold the party. Many observed that Pradip would want us to party (he loves a party!), and the group decided to go ahead, but with fewer games than planned. During the process of deciding, we kept silence for a few moments to meditate together in order to be with Pradip in spirit and come to a consensus.
LEGISLATION and ADVOCACY CELL

The Legislation and Advocacy Cell works with grassroots and governmental organisations and people with disabilities to develop security and equalisation of opportunity for people with disabilities throughout society. It has succeeded in forging a network with over 150 organisations, activists with disability and parents from all over India to amend legislation and policy for greater impact on the lives of people with disabilities and their caregivers.

Specifically, we have worked to 1) try and amend legislation restricting rehabilitation training programmes by the Rehabilitation Council of India (RCI) Act, 1992, and to 2) create amendments to a bill of rights for people with disabilities (the Equal Opportunities, Protection of Rights and Full Participation of Persons with Disabilities Bill, 1995).

Students are working on self-advocacy by participating, for example, in public events, and experiencing some of the handicapping limitations imposed on them by negative attitudes and inaccessible buildings and roads. When they experience a limitation, they write letters to educate public officials about the problem as part of their CSE curriculum, and then they present these letters to the people concerned.

PROFESSIONAL NETWORKING CELL

The Professional Networking Cell was organized during 1995 to coordinate and manage the many ongoing information dissemination, consultative, and advisory activities which have evolved in each project as our experience has grown. This involves developing mutual partnerships with outside groups and individuals, professionals and trainees, and the public at large.

People and organisations from all over India, from other developing countries and abroad are consulting with SSNI staff, and we are working with a large network of resource persons who offer their expertise to our staff and children and families regularly. We share our knowledge and skills through regular training programmes and in-services with trainees and professionals from all over the country. Our library is a growing resource for rehabilitation students and professionals in northern India.

As a result of the spirit which many of us share, we are building mutual partnerships with others and experiencing the growth of a genuine community of individuals and organisations with a common mission to improve life with and for people with disabilities.

NIDDR

The Legislation and Advocacy Cell and the Professional Networking Cell have also been combined to form a project called NIDDR: Networking, Information Dissemination, Disability Development and Rights Advocacy. NIDDR's second meaning comes from the Hindi word referring to a meditative state of heightened awareness which allows for regenerating energy and reinforcing inner strengths.

![A young woman with a mental disability presents her views and experiences to legislators and MPs in 1994 to advocate for amendments to the RCI Act of 1992. Mrs. Hira Joshi (right, a parent) and Dr. Jaya Srivastav, Director of Ankur Urban Slum Project (left) also participated.](image-url)
GROUP on AWARENESS RAISING and PUBLICITY

In keeping with SSNI's vision of its role as an apex body in influencing public opinion, we are widening our efforts for indirect impact through awareness raising. Each staff member persuades a friend to learn more about disability, and each department takes responsibility for raising awareness whenever possible.

The Group on Awareness Raising and Publicity (GARP) was created during 1995 to coordinate SSNI's public education activities concerning the rights and abilities of people with disabilities. GARP assists in creating communication tools for public education about cerebral palsy, disability in general, and the work of SSNI. It produces SSNIPETS, a quarterly newsletter, and develops brochures, slide shows, films and poster campaigns. The following text, for example, was given to hundreds of people from all walks of life at a health mela in Delhi in 1995, along with information about cerebral palsy and SSNI's work.

CHANGING PERCEPTIONS

Examine the image you see in your mind when you think of a person with polio, cerebral palsy, or one who is blind or deaf or mentally retarded. Ask yourself, "What are the assumptions I make about this person's ability to do work, have friends, marry?" Then, practice imagining this same person working successfully in your company, being your friend or part of your family. Finally, rid yourself of the notion that persons with disability need charity. They don't. They need work, friendship and choices.

Rehabilitation is not complete until the person with disability can work in whatever capacity their limitations allow. For some this can mean becoming a high ranking official, for others it means self-employment. It can be as simple as becoming productive in the home.

"For rehabilitation to be successful, a community must recognise and accept that people with disabilities have the same rights as other human beings..... It has been found that the most effective way to bring about such a change in attitude is for members of the community themselves to take on the task of rehabilitation." [Einar Helander, from Training in the Community for People with Disabilities]
INTERNAL ORGANISATIONAL ACTIVITIES

HUMAN RESOURCE DEVELOPMENT

MATERIAL RESOURCE DEVELOPMENT

ADMINISTRATION

SSNI’s urban-based staff.
HUMAN RESOURCES DEVELOPMENT (HRD)

A conscious and structured strategy for Human Resources Development at SSNI commenced in January, 1995 following an inspiring management workshop held for staff.

Human resources development at SSNI means developing each person’s full potential. It includes training, personal development and spiritual activities, and utilizing consultancies from local and international experts in CBR, research and training, and management for NGOs.

Disinvesting professional power and sharing information and decision making with the children and their families are part of our HRD efforts. The primary children in CSE are now planning, writing and conducting their own performances for school assemblies, instead of having teachers do much of the work. Staff from all projects are taking on new responsibilities for training and administration and stretching their own capacities.

SSNI’s organisational structure is undergoing a change from a conventional hierarchical, top-down model, to a consensual, collaborative bottom-up model. The creation of a decentralized management team in the form of an executive committee - as opposed to one person - responsible for decision making with staff is one of the concrete ways we are working toward change.

Consultancies from international CBR experts in training and evaluation are giving staff new ideas, skills, perspectives and confidence. Study tours to CBR projects in other developing countries and a few special training awards for staff to do post-graduate study abroad are helping us build up our expertise.

The number of staff at SSNI has grown very little (from 124 in 1992/93 to 141 staff in 1994/95) to accommodate the major changes which the organisation is experiencing. Thirty percent of the increase has been for administrative staff and 41% for domestic and maintenance staff to handle the larger physical facility we now inhabit.

Human resources development for staff at SSNI translates into enabling each of us to stretch ourselves to serve the students, trainees, their families and the community in diverse ways. An essential aspect is learning ways to work with caring and to build our skills in mediation and conflict resolution. The emphasis we place on spiritual values helps us to accomplish this.

Spiritual values and personal development are part of the curriculum for students and trainees, and are offered to parents during monthly meetings.

Mediation skills are modelled for caring approaches to interpersonal problem solving for staff, students, parents and trainees.

PROFESSIONALISM and ACCOUNTABILITY

Professionalism and accountability are only words. When put into practice, they derive from internal drives which may come naturally to some, and from actions which can be modeled and reinforced for everyone. The attitude of acceptance, caring and service are basic to SSNI’s work, and form a foundation for instilling and maintaining a high degree of professionalism and accountability among all staff. These are not accomplished by the feeling of scrutiny or a focus on correction. Without ignoring problems, the focus is on building strengths, trusting the impulse of each staff member to do their best, and building on that trust.

"Nevertheless, everybody questions everything they do - there is no complacency," Gloria Burrett, the director, says. Staff accept the requirement for accountability, reporting monthly, for example, to their project head on their own performance for that month.
SSNI FACES a CRISIS

A driver for the rural CBR project at Dayalpur had been performing erratically and driving dangerously at times. Staff finally decided he had to be let go. They spoke with the Panchayat leaders who take part in the project’s decisions, and the Panchayat wanted to give him another chance. For some time, the driver improved but then his driving again deteriorated. Staff decided that for the safety of everyone he had to be fired, and took the necessary action.

Behind the scenes, an old feud was enervated by the sacking of the driver. People began dividing, and the Panchayat took sides against the project. Drivers for all of SSNI’s vehicles became involved and made a precipitous threat to quit on 2 weeks’ notice unless a heavy duty allowance was given for driving to the rural CBR project. SSNI had recently increased the drivers’ pay to include a rural and a bus driving allowance, and believed the demand unreasonable. But driven by the belief that we must listen to needs, SSNI managers consulted a lawyer for NGOs regarding the validity of the drivers’ demands, and found that the increase was justified.

A meeting was held with all drivers, to discuss SSNI’s values, illustrating that the organisation does not believe in threats or in unionizing for rights, but in a human process. It expects that accepted procedures like giving one month’s notice will be followed, and that management will listen respectfully to staff needs. A separate meeting would be held afterwards to discuss salary changes, but first the values had to be reinforced. Drivers who insisted on unionizing were told to go ahead and leave so that others could continue the discussion. No one left. Salary increases were decided in the following meeting.

These events occurred just before Dusshera, and the drivers took the holiday week to decide on their course of action. Managers’ hearts were in their mouths, not knowing if the children would have drivers to get to school after the vacation. The drivers came back, saying that “we’re thinking differently now. We want to drive to Dayalpur (the rural CBR project).” The crisis was over, and we reflected on our process in order to reinforce in our own minds what had worked.

Maintaining equal values across the board in dealing with all staff, toughness in management and the softness to respond when a need is expressed are all integral to maintaining a human element in resolving the conflicts which are a part of the life of every organisation.
EMPOWERMENT

What is empowerment? What does it require? How does it look? “When I have the strength and opportunity to make decisions about my own life, I feel empowered,” says a communications consultant and counselor with SSNI who has a severe disability from infantile rheumatoid arthritis. He adds that a missing element is often the careful preparation and learning required for people to use the “empowerment” which others may try to create for them. To be given a microphone at a public event, for example, does little good if the person using it has not prepared to speak and cannot communicate clearly.

Empowerment is a popular word for people doing service and development work. We have been asking ourselves for several years how this word looks in practice, from the point of view of the people who care to be empowered in some way. The starting point for empowerment is to be seen and to be listened to with the whole self of the listener. At SSNI, listening carefully to the early, unspoken needs and challenges of people with disabilities helps them begin to develop the confidence to communicate on their own behalf. Then in more difficult situations, they have the ability to get a message across. “Am I really listening?” is the question we must always ask ourselves.

But listening or being heard are not enough, they are only vehicles. Building inner strength requires developing the ability and taking the responsibility for communicating for oneself. And it requires finding or creating opportunities for practice.

VWTC trainees participating in an ongoing counselling group had become comfortable sharing their personal and most private feelings, questions and worries with a counselor and SSNI staff who were open in sharing themselves and were “unshockable”. Eventually the trainees began wanting to express themselves to their parents to achieve some of the closeness and understanding they were discovering in the group. Parents and trainees are meeting now, participating in role plays and sharing their feelings and thoughts with guidance from the staff. Earlier, staff had been a buffer, communicating for the trainees with their families. The direct one-to-one communication which is now happening means the beginning of empowerment. One surprise for some of the trainees has been to discover their parents have feelings, too.

A senior physical therapist who participated in this group for 3 years says, “It opened my eyes. It was only over time that I realized I had related to the VWTC trainees as children. We always said we were equals, but never really felt it. This was the first time I could relate to them as friends and realize I had much deeper things to share. Now, when I read theory, everything makes sense.”

Raju Saraf enjoys a moment of understanding during a home visit, with the help of interpretation by his multi-purpose rehabilitation worker from the VWTC. Since Raju uses a board filled with letters and numbers instead of speaking verbally, listening to him takes time and patience; but with great rewards for everyone involved.
RIGHTS and RESPONSIBILITIES

SSNI students were happy when 2 art galleries in Delhi decided to exhibit their paintings. But then they discovered that the galleries were physically inaccessible, and they would not be able to see their own work on the galleries' walls. They converted their disappointment into letters explaining the importance of accessibility, and so far have received at least acknowledgment from one of the galleries.

When the tribal people from the Narmada Dam Project area came to Delhi, SSNI students and trainees arranged to have a meeting with them, with the help of a staff member knowledgeable about the issue. These tribal people’s homes had already been flooded by the dam project. After listening to the Narmada people talk about the devastation the dam has meant to their lives, SSNI students took the microphone and began to ask questions. One student, with a severe disability from cerebral palsy, asked “What can we do to help you?” A tribal person took the microphone back, and struggled at first to find an answer. Finally he said, “you are doing more than enough by meeting us this way.” The student insisted on responding, and said, “Don’t think that just because our bodies look this way or that we have trouble speaking that we can do nothing. Please let us know what we can do for you.” Then a real dialogue started between the students and the tribals. The end result was a large drive to collect food and clothing which the tribal people badly needed, organized entirely by the students themselves.

THE ODA GRANT

SSNI applied to the Overseas Development Agency (ODA) of the UK in 1984 to fund a major expansion of its building in order to accommodate its growing projects. Over a period of seven years the ODA sent several teams of experts in rehabilitation, finance and architectural planning to scrutinize our project. The ODA finally approved a large grant for SSNI in 1991, to enhance our capacity to provide services especially to people with cerebral palsy, and with a focus on the poor. The grant completely financed the construction of a 40,000 sq. ft. extension to SSNI’s building in Delhi, the establishment of CBR outreach to urban slums, 5 major consultancies, 3 overseas study tours and 5 overseas training awards. The grant was designed to support SSNI’s evolution as an apex body and regional rehabilitation centre, serving northern India. It specified goals for the Centre for Special Education, the SRS, the VWTC, Home Management and Resource Centres, as well as providing space for SSNI administrative offices and staff quarters. The grant also financed equipment, furniture and vehicles for the extended projects and facilities.

The ODA grant covered a period of 3 years, commencing in 1993, and is due to be complete by the end of March 1996. New growth of projects will plateau during 1996 as our emphasis shifts to stabilize the massive growth and change we have undergone for the past 2 to 3 years.

MATERIAL RESOURCE DEVELOPMENT

Fundraising is active, as we work to create a foundation for sustaining our growth in the coming years. Grants from the government, a large annual cultural event, and greeting card sales are our mainstays. We regularly write grant proposals to cover special projects. The ODA grant was by far the largest we have received. We are also working to build up our corpus fund for financial sustainability and flexibility in expansion of our activities.

There are a great number of people who have donated financially to SSNI over the years, either directly or by in-kind contributions. These people, many of whom have contributed very substantially, have created an essential part of the financial base from which SSNI operates.

ADMINISTRATION

Administration provides the central infrastructure for SSNI’s service delivery projects and all its operations. These include personnel administration, office management, purchasing and estimates, building and equipment maintenance, management of the van fleet, the carpentry workshop, institutional rules, housekeeping and hospitality.

Administrative staff are involved in the full range of organisational changes SSNI is making. The philosophy of increasing equality and consensual decision making is giving a voice to people at every level of the organisation.
BUILDING EXPANSION

History

In 1983, SSNI began raising money for a building on the land allotted to us by the D.D.A. The foundation stone was laid on October 7, 1983, and construction began in 1984. Within a year we were able to move into the spacious 16,000 sq.ft. area which represented Phase I of the whole building.

Over the following 2 years, every part of this building was occupied with new projects and activities, and again we were bursting at the seams. The cost of building had escalated to the point where completion of Phase II had become a distant dream. The Ministry of Welfare suggested that we apply to the Overseas Development Agency in the UK for funds. The ODA’s funding for the building came as a result of their belief in the vision, focus and viability of SSNI’s future plans and need for space.

We were fortunate to have the renowned architect Romi Khosla design our building, which is constructed in an oval shape, to represent a nurturing environment. The building was complete by March 1995.

Utilisation

The 56,000 sq.ft. we now have available to us for SSNI’s regional rehabilitation centre has multiple uses. Beyond housing SSNI’s direct service projects, apex activities and administrative offices:

- It has allowed for expansion of the CSE and the VWTC projects.
- As one of the few disability accessible buildings in Delhi, it is used to host meetings and seminars with participation from people with disabilities.
- Older students have their own “adult free” area.
- Outstation families are housed in 4 units, collectively called the RORU, or Residential Outstation Rehabilitation Unit, to allow their participation in monthly clinics which last 6 days.
- SRS trainees from all over India are given units in a small hostel housed in the building.
- Guest rooms are available for out-of-station consultants and other visitors.
- A few quarters for staff are provided to enable people without affordable Delhi residences to work at SSNI.
- Outside groups working in the area of disability rehabilitation began to use the building for meetings and workshops in 1995.

SSNI’s new building.
OVERALL CHALLENGES and RISKS FACING SSNI

As the numbers of students, trainees and children and families in our projects grow: we must assure that we are working to improve quality of life, and to increase mainstreaming into homes, schools, workplaces, and social life in the community for people with disabilities. Some of the challenges we face are:

- To sustain a loving and human approach as we meet the requirements and pressures for building administrative and operating systems.
- To maintain SSNI's role as a model and resource, a strength for other organisations. To guard against becoming a magnet, overshadowing smaller groups or overwhelming ourselves.
- To balance our new focus on macro-level issues like legislation and advocacy with our long-standing micro-level work in direct services.
- To assure that senior staff keep in close touch with parents, especially poor and uneducated parents, to continue to learn from them and respond to their needs.
- To evolve a management system which is driven by SSNI's basic values and philosophy.
- To distribute authority along with responsibility to supervisors, coordinators and administrators.
- To develop long range plans, allowing for realistic work loads.
- To create more effective communication within and between projects of SSNI.
- To evaluate SSNI's salary structures and find ways to increase salaries to a community standard: for increased staff retention, ability to attract skilled staff, and to do justice to the commitment of all the staff who continue to dedicate their work to SSNI.
- To establish financial self-sufficiency.

Some questions we have been asked by our evaluators to consider include:

How can staff learn to "give their skills away", while at the same time maintaining standards of excellence?

Can we develop a new and wider role for staff partly by increasing the identification, recruitment, training, support and motivation of volunteers? How can we manage this?
THE PEOPLE WHO WORK with SSNI

URBAN BASED STAFF (Delhi Centre)

RURAL BASED STAFF (Dayalpur)

GOVERNING BODY/ GENERAL BODY

VOLUNTEERS

RESOURCE PERSONS/CONSULTANTS

Aruna Parashar, CSE alumnus, and now a staff member at SSNI, with a teacher who has worked to help her overcome large and small hurdles, with the help of a lot of laughter, for many years.
"When I came to the Spastics Society school for the first time, (in 1980) my heart was a little disturbed. I saw all these children and thought to myself ‘God, what have you done to them?’ On the second day, Mita (Nundy) introduced me to the children. My body was rather heavy, I was very fat then, and all the children started laughing. They said, ‘What is this person going to do to help us?’ When they said that, I told them, ‘Don’t you worry, I’ll do everything you want.’ I picked up one child and helped take him to the toilet. The children were surprised.”

“In those days, the school was in someone’s house and we only had one van. So we had to take taxis to transport the children to school. I got so attached to them that at night I couldn’t sleep properly, thinking I might be late and no one would be there to help the child get out of the taxi. The children were small, and we used to take 8 or 10 at a time in the taxi, because it was too expensive. I held them on my lap, and sometimes they would accidentally ‘toilet’ in the taxi, and my clothes would be dirty. But I didn’t bother, and just waited to the end to take the child into the school.”

“The work was easy then, but it was hard to understand the children’s speech. It took a long time, but as I came to know them I started understanding what they wanted. There are some who speak with gestures. Others speak with their eyes.”

“The school has grown much bigger now, and the children are bigger too, so there is more work and heavier physical labor. I have been here for 15 years now, and as I get older, I wish for some financial security when I have to retire. But these have been my best years. And now, when there are new staff members, I help them understand how to take care of the children. They are my children. Whatever needs to be done for them, I do with happiness.”
SSNI STAFF

TECHNICAL STAFF (Delhi Centre/Urban)

REHABILITATORS (Associates*)
Physical Therapists, Occupational Therapists, Speech/Communication Therapists, Special Educators, Social Workers, Psychologists, Basic Developmental Therapists, Carpenters, Multi Purpose Rehabilitation Workers, Teaching Assistants. (54 Staff*)

SUPERVISORS (Co-ordinators)
Departments: Therapy, Education, CBR Training, Social Work, Vocational Work Training Unit. (12 staff)

PROJECT HEADS (Co-ordinators for Projects and/or Members of the Executive Committee)
Projects: Home-Management, Dayalpur, Community Based Rehabilitation (CBR), Vishwakarma Work Training Centre, Centre for Special Education. (5 staff)

DIRECTORS (Overseers)
Services, Administration and Finance, Training, Fund Raising. (4 staff)

CHAIRPERSON (Overseers/Chairperson, Governing Body)

NON-TECHNICAL STAFF (Urban)
Peons, Attendants, Chowkidars, Maintenance, Drivers. (36 staff)

ADMINISTRATION and FINANCE STAFF (Urban)

ASSISTING (Associates)
Central Office, Service Projects, Finance, Administration, Telephone Operator, Maintenance, Fund Raising, School of Rehabilitation Sciences and Library, Reception. (17 staff)

MANAGERS / SUPERVISORS (Co-ordinators)
Transport, Finance, Secretarial, Administration Departments. (5 staff)

DIRECTORS/CO-ORDINATORS
(Co-ordinators and/or Overseers)
Administration, Fund Raising. (2 staff)

RURAL CENTRE at DAYALPUR

Volunteers, Rehabilitators and Support Staff (Associates and Co-ordinators)
Rehabilitation, Education, Parent, Staff and Vocational Training, Communications, Administration, Carpentry, Office, General Support, Drivers. (24 staff, not including the urban staff responsible for teaching, supervising and providing rehabilitation therapy for the rural project.)

The rural staff at Dayalpur.

* Titles in brackets reflect new terminology agreed upon in 1993 and put into practice in July/August, 1995.
** Number of staff listed is as of July 1995.
GOVERNING BODY OF SSNI

Chairperson
Ms Mita Nundy
B.A. Hons (LSE), M. Phil (J.N.U., Delhi)
Director, Research and Training, SSNI

Vice-Chairperson
Dr Lotika Sarcar
Ph.D. (Cambridge); Bar-at-Law
Senior Fellow, Centre for Women’s Studies

Treasurer
Ms Divya Jalan
B.A. (Ed. Hons., Cal.);
Dip. Physical Handicap (London);
M.A. (London)
Ex-Director of Services, SSNI

Secretary
Ms Anita Shourie
B.A. (Lucknow)
P.G. Certificate in UNICEF-sponsored course
in Special Education
Parent of a child w/ CP
Ex-Head, Centre for Special Education, SSNI

MEMBERS

Dr Samiran Nundy
M.A., M.S. (Cambridge)
F.R.C.P. (Edinburgh)
F.R.C.S. (London)
Editor, National Medical Journal
Head, G.I. Surgery, AIIMS

Ms Kamla Bhasin
M.A. Economics
Parent of a child w/ CP
Programme Officer for
South Asia, F.A.O

Mr S R Sharma, IAS
M.A. English Literature (Agra University)
Chairman, Delhi State
Civil Engineering Corporation,
Government of Delhi, State of Delhi

Ms Manjulika Dubey
M.A. English (Delhi University)
Editor

Ms Gloria Burrett
M.Sw. (Delhi University)
Courses in Rehabilitation (UK)
Ex-Director of Services, SSNI

Mr. Ricky Surie
B.Sc. Electrical Engin. (IIT, Kanpur)
M.B.A. Business Admin. (Harvard University)
Managing Director, Intl Equity Partners, L.P.
International Management Consultant

Ms Radhika Roy
B.A. Hons. (Delhi University)
Dip. Speech Therapy (London)
Producer - NDTV
Ex-officio Members: SSNI Executive Management Committee (2 from the following group)

Ms. Manavi Jalan
M.A. Psychology (Delhi)
P.G. Dip. in Education of Physically and Neurologically Handicapped Children, SSNI
Member, Executive Council
Co-ordinator, Augmentative Communication Administration, SSNI

Ms Madhu Grover
M.A. Psychology (Delhi)
P.G. Dip. in Education of Physically and Neurologically Handicapped Children,
Member, Executive Council
Co-ordinator, Urban Services

Ms Sujatha Padmanabhan
M.A. Psychology (Delhi)
P.G. Dip. in Education of Physically and Neurologically Handicapped Children, SSNI
Member, Executive Council
Co-ordinator, Teacher Training Course, SSNI

Ms G Syamala
B.Ed., M.A. Psychology (Delhi)
P.G. Dip. in Education of Physically and Neurologically Handicapped Children,
Member, Executive Council
Co-ordinator, Rural Services

GENERAL BODY

The General Body of SSNI consists of all members of the Governing Body and six additional non-voting members.

Major General S.W. Burrett,
PVSM, AVSM (Retired)
Bachelor of Engineering,
College of Military Engineers (Pune)
Diploma, Senior Highway Engineering Course
CRRI (New Delhi)
Member, Institution of Engineers (India)

Ms Ranjana Das
B.A. (Education), (Calcutta University)
P.G. Diploma in Special Education
(SSSI, Bombay)
Special Educator

Dr Sunanda Reddy
D.C.H. (Osmania University)
D.N.B. (Paediatrics)
NBE (National Academy of Medical Services)
Research Associate (ICME)
Private Practice/Development Paediatrician, SSNI

Ms Vandana Bedi
Dip. OT (FH, Delhi)
P.G. Course in Management of CP,
(SSSI, Bombay)
Director, BDT Training, SSNI

Ms Shobhana Lahiri
B.A. English Lit. (Loreto College, Lucknow Univ.)
M.A. English Lit. (Miranda House, Delhi Univ.)
Ex-Director, SSNI Finance and Administration

Ms Renee Burgard
B.A. Psychology (Stanford University)
M.S.W. (University of Calif., Berkeley)
Freelance: R. Burgard/Communication Arts

Note: Governing/General Body charts reflect membership effective December, 1995
VOLUNTEERS

SSNI would not exist without both its volunteers and a spirit of volunteerism which pervades the work of all its dedicated staff, who go beyond the confines of the "job" and transform their work into service.

All kinds of people volunteer for all kinds of work at SSNI. Sheila Gondotra, for example, has been coming to the CSE daily for five years to teach English. She has a slight limp in one leg, which does not stop her. "The moment I'm away from the kids," she says, "I start limping in the other leg, too." Recently when one student needed a typewriter, she donated the one which had been her father's and which she had kept carefully put away for years in his memory.

Other volunteers do landscaping, register children for medical clinics, staff community day centres, make films. The list goes on. One young Indian Express reporter roars in twice a week on his 2-wheeler to help children with typing. In the rural CBR project, illiterate women who have been trained by project staff are doing functional therapy for people with polio, linking with health clinics for prevention and early detection of disability. From teenagers to people who have long been retired, there is work to do here. Many people donate their professional skills and time to SSNI. Equally important to our families and students is time spent going to a movie, babysitting to give respite, or driving a child to school. As of July 1995, 156 people were volunteering for SSNI.

RESOURCE PERSONS/CONSULTANTS

Another kind of volunteering is the services which professionals offer, at no charge, from their respective fields of medicine, psychology, rehabilitation, law, media communications, management, HRD and personal development, vocational training and employment. Eighty-eight people were sharing their time and skills with SSNI as of July 1995.

Ajay, who lives in the Dayalpur area, has severe quadriplegia. He was interested in school, and with the help of tutoring (from people like the neighbour who is volunteering to help him here), had made it to the 10th Class exams at the time of this picture.
**LIST OF ABBREVIATIONS**

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Full Form</th>
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<tbody>
<tr>
<td>ADD</td>
<td>Action for Disability Development</td>
</tr>
<tr>
<td>BCD</td>
<td>British Council Division (Managers of ODA grant)</td>
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<tr>
<td>BDT</td>
<td>Basic Developmental Therapy</td>
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<tr>
<td>CAPART</td>
<td>Council for the Advancement of People’s Action and Rural Technology</td>
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<tr>
<td>CBR</td>
<td>Community Based Rehabilitation</td>
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<tr>
<td>CBSE</td>
<td>Central Board of Secondary Education</td>
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<tr>
<td>CRC</td>
<td>Convention on the Rights of the Child</td>
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<tr>
<td>CSE</td>
<td>Centre for Special Education (the SSNI School)</td>
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<tr>
<td>DOSTI</td>
<td>SSNI based friendship club, started by SSNI alumni.</td>
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<tr>
<td>GOI</td>
<td>Government of India</td>
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<tr>
<td>HCPA</td>
<td>Handicapped Children’s Parents Association</td>
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<td>HM</td>
<td>Home Management Programme</td>
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<tr>
<td>HRD</td>
<td>Human Resources Development</td>
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<tr>
<td>ICCW</td>
<td>Indian Council of Child Welfare</td>
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<tr>
<td>NGO</td>
<td>Non-Governmental Organisation</td>
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<tr>
<td>NIDDRA</td>
<td>Networking, Information Dissemination, Disability Development and Rights Advocacy</td>
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<tr>
<td>ODA</td>
<td>Overseas Development Agency</td>
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<tr>
<td>RCI</td>
<td>Rehabilitation Council of India</td>
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<tr>
<td>RORU</td>
<td>Rehabilitation Outstation Residential Units</td>
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<td>RRW</td>
<td>Rural Rehabilitation Worker</td>
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<tr>
<td>SCF</td>
<td>Save the Children Fund</td>
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<td>SRS</td>
<td>School of Rehabilitation Sciences</td>
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<td>SSNI</td>
<td>Spastics Society of Northern India</td>
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<tr>
<td>TCTP</td>
<td>Technical Cooperation Training Programme</td>
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<td>TTC</td>
<td>Teacher’s Training Course</td>
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<td>VRW</td>
<td>Village Rehabilitation Worker</td>
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<tr>
<td>VWTC</td>
<td>Vishwakarma Work Training Centre</td>
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SSNI'S VALUES and PRINCIPLES for ACTION

To equally value all work and motivation, regardless of job titles or educational background.

To see all people (parents, clients, colleagues, outsiders) as belonging to one caste, one family - the caste and family of humanity.

To serve quietly, without personal publicity, and to struggle to work without ego.

To strive to work with clients/colleagues with unconditional love.

To think with openness, critically and analytically about all aspects of our work.

To work with high professional standards, realizing that attitudes are at the heart of what makes our work succeed or fail.

To give the best to our work without the expectation of reward.

To work whenever possible for consensus decision making.

To be especially alert about the negative perceptions, feelings and thoughts which at times arise in most human relations. To strive to give negative feedback only after reflection; to the person involved and not to third persons; and only when necessary for effective working.

To share feedback with detachment and caringly for the other person's feelings. To resolve conflicts through caring and direct discussions, with understanding.

To respect, tolerate and appreciate individual differences.

"And all work is empty, save where there is love." Kahlil Gibran
The Spastics Society of Northern India
Balbir Saxena Marg, Hauz Khas
New Delhi - 110 016

Rural Community Based Rehabilitation Project
Dayalpur Primary Health Centre, Ballabgarh Block, Faridabad, Haryana