Reminiscences

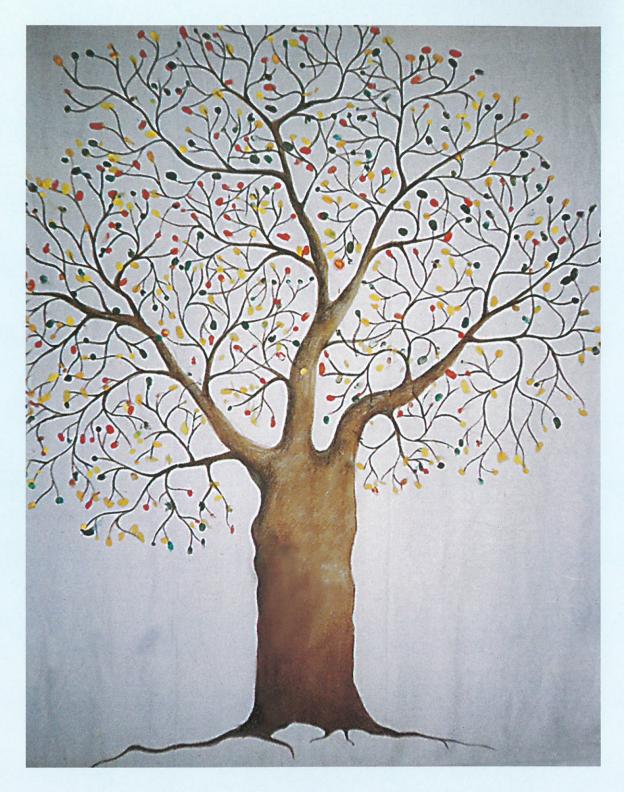








Working together with differences intact



As an act of solidarity, on the 14th of November '98, as SSNI turned twenty, students, family members, staff, volunteers and well wishers got together to create a family tree. Each one of us depicted, with a thumb impression, the reasons why we are here. Different colours were chosen to represent the different reasons:-

Light orange : Spirit of togetherness, trust and joy Dark orange : Dynanism and openness to change

Yellow : Sense of service and giving
Green : Practising deep rooted values

Dark Green : High professional standards with development of self potential

किसने लगाया ये वृक्ष

जो जादू का है।

जिसके पीले पत्ते भी,

थके और लाचार पथिक को,

छाया, ठंडक, और सुख देते हैं।

कौन है वो बताओ ना ?

जब मैंने पूछा तो,

किसी ने कहा है, "है-कोई"।

पर कहाँ है ? कौन है ?

कभी दिखाई क्यों नहीं देता ?

ओह! अब समझ में आया,

वो जड़ है जो ज़मीन के अंदर है।

तभी तो नज़र नहीं आती।

इस पेड को हरा-भरा रखने के लिए,

और उसके भरण पोषण के लिए,

और वो खड़ा रहे सीधा ज़मीन पर इसलिए,

अंधकार में रहती है।

और बदले में अपने पेड़ से,

जुड़े रहने का सुख चाहती है-बस !!

मीता नन्दी दीदी के लिए मीनाक्षी अभिभावक The reality and the vision represented by the Spastics Society of Northern India today is a result of the dreams and the sheer hard toil of the growing band of people who made this Society an articulation of their mission.

The SSNI was started by a handful of people, filled with a need to work for children with neurological disorders. As the years grew, their vision expanded. From the initial aim of reaching specialised services to persons with cerebral palsy, today it encompasses the aspirations, needs, rights of the persons with disability, it recognises the right of self-advocacy.

What started as a school has become a movement. And the small group of individuals has grown into a veritable army of revolutionaries.

Essentially, the SSNI is a kaleidoscope of people, representing different ideas, different approaches, different disciplines. It is an institution built by the people, for the people. It represents the poet's dream of a society where people co-exist and flourish in peace, working together for a common objective with all their differences intact.

The 20th anniversary of SSNI was thought to be best commemorated by SSNIPPETS as a celebration of people, a celebration of the true spirit of SSNI.

The following pages seek to represent the different experiences, the different perceptions, the common vision shared by SSNIANS, as all of us - connected directly or indirectly with this living body - call ourselves. With malice towards none and the ability to laugh at ourselves firmly in place.

Editor

Contents

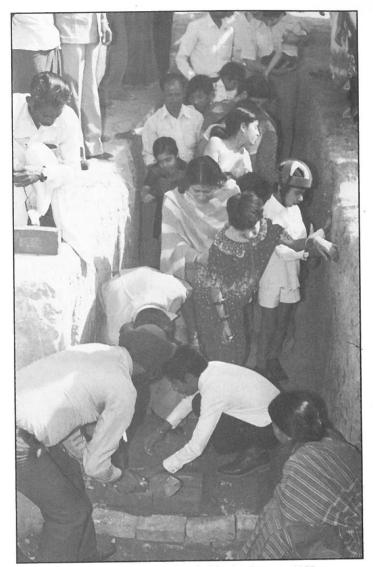
How it all began : 1 / The green room supporters : 2 / Chanda didi remembers : 4 / A typical day at CSE : 5/Evergreen memories : 7 / Looking ahead : 8 / There is light : 8 / A peep into the past : 9 / Lighter moments with Mita : 13 / Worlds apart : 14/ Exam blues : 15 / Just let the steam out : 15 / A touch of gold : 16 / To let : 17 / So much to learn : 18 / Sunrise : 18 / Reach for the sky : 19 / Beyond words : 19 / माँ के उदगार : 20/ एस. एस. एस. एस. अर्ड. की बीसवीं वर्षगाँठ : 21 / Acknowledgements : 22

How it all began.....

In November 1978 services in Delhi were first launched under the umbrella of the Spastics Society of India, Bombay. It was a daunting challenge. Four trained dedicated women, amongst them Mita Nundy and Minu Jalan, did an immense amount of leg-work: the initial public awareness-raising through medical conferences; the locating of 16 cerebral palsied children through posters in rehabilitation departments in hospitals, word of mouth, announcements in different geographical areas of Delhi using megaphones; finding suitable premises; raising the necessary funds for equipment and transport; applying for grants for capital and recurring expenses; finding trained therapists.

A 4-bedroom flat in Safdarjung Development Area served as our premises for the first 5 years. The number of admissions grew by leaps and bounds. The bedrooms functioned as classrooms, the drawing and dining rooms became office space, the kitchen was the speech-therapy room, the garage was for physio-therapy, a bathroom served as a store. Later, a shack put up in the aangan served as the occupational therapy room. Gross motor activities spilled onto the driveway and the small patch of lawn, and later, to the park across the street. In the five years we spent here, our numbers grew so much that the Home Management Programme was slated in the afternoon shift. Meanwhile, the Dayalpur Rural Project had already been launched. Necessary staff-training courses were conducted in borrowed premises of NCERT. It was a time of such dizzying growth that Bombay suggested we register as a separate Society. In 1982 we were formally registered as The Spastics Society of Northern India.

Simultaneously, an energetic drive was initiated, not only to fund the recurring and much-needed capital expenditure (such as vans), but also to find land on which to build a centre. We found that our work and the children's achievements evoked in everyone who visited the centre a great desire to help. Thus, Delhi Administration generously granted us a 1.25-acre plot of prime land in Hauz Khas, with an adjoining 0.75-acre area designated as ours to use specifically as a playground. When we despaired of raising the large resources required for building purposes, friends raised unexpected large chunks of money for us. Rs. 5 lakhs was donated by Kuwait-based friends, Aruna and Ghazi Sultan, Rs. 13.5 lakhs was unexpectedly gifted to us by the Sheikha of Abu Dhabi who attended a bazaar organised by

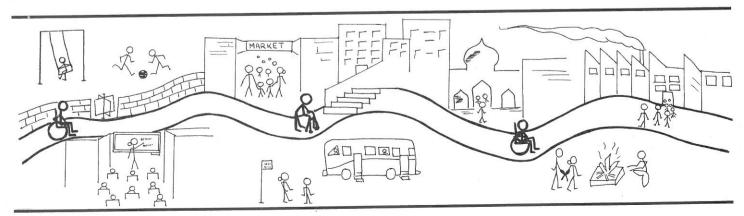


Children laying the first bricks in the year 1983

Nasima Aziz, the Indian Ambassador's wife. (The modest purpose of this bazaar had been to raise funds for a van!) NORAD granted another Rs. 12 lakhs, and with this corpus we began the first phase of the building.

In 1983, on Baisakhi day the construction commenced with a bhoomi-puja, followed by some children laying the first few bricks. By the summer of 1984, in record time, we had moved, lock stock and barrel, into our new premises.

Anita Shourie Staff member



The green room supporters

It is 20 years of SSNI - a lot of hard work and dedication put in by hundreds of people who have worked or are still working at SSNI.

There are, however, many supporters who by choice remain in the background. Behind every successful staff of SSNI stands a tolerating and supporting spouse, understanding sons, sons-in-law, daughters, daughters-in-law, thoughtful in-laws and parents accommodating grandfathers-in law and ever obliging friends.

This article is dedicated to those 'Green Room' people without whom the show would never have gone on, and, the staff drop out rate would have doubled.

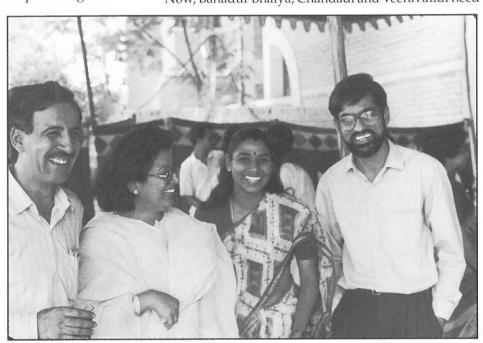
Their support starts at the time of the nerve-racking yet challenging BDT and TTC course. Not only obliging by numbering pages or colouring pictures of various kinds, the family is generous enough to disappear on Sundays so that "Mummy dear" can finish her reading.

Renu Singh, (batch of '96-'97) is ever grateful to her Man Friday for holding the family together and providing hot

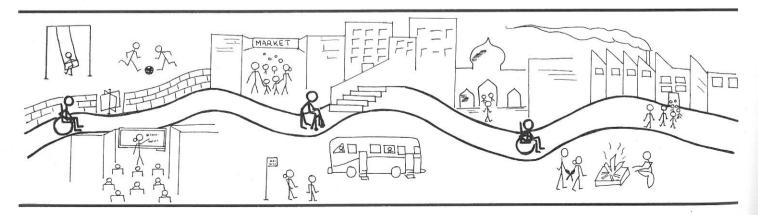
meals while she attended long lectures. Sonali's (batch '94-'95) husband would drop her every morning from Gurgaon and then drive back to his place 5 km beyond Gurgaon. What stamina! Vinita Rawat (who, incidentally, completes her 20 years with SSNI in '99) gave her usual wicked grin and said that for years she has hogged all the credit for doing up the stage at every fund raising event, yet it is her husband and son who do all the actual running around to the various tent houses and florists. She recalls an incident when her student Hemant and his family were caught in a fire 11 years ago. It was her son Suneel who sat holding Hemant's hand while Vinitadi was with his mother. Nirmaldi recalls not an isolated incident but the everyday support of her husband and family. He adjusted his day and work so that he would be there when their kids got back from school. Taking elderly parents to the hospital was done by Nirmaldi's husband since she could not take off. One husband who deserves special mention is Bharathy's who was left high and dry on their wedding anniversary this year, while Bharathy went off for a night vigil for solidarity on disability issues.

All our families have heard each and every detail of the children of SSNI, be it Mithul's swimming, Divya's success in learning French, Mithun's volunteer problems or Anand Deep Singh's wheelchair-bound mother whom he had to take care of. I don't think there is a single family who does not feel emotionally involved with our kids. Sanjuktadi's husband had tears in his eyes as he listened to the plight of a fatherless child with CP. It is his encouragement and appreciation that has helped Sanjuktadi to relearn driving at the young age of 58 and now she proudly brings their ca r to school every day. Well done! Age is certainly no barrier to learning.

Now, Bahadur Bhaiya, Chandadi and Veeravatidi need



SSNI staff with their spouses at an SSNI event



special mentioning. They too are about to complete 20 years with SSNI. When they joined years back they were offered jobs as domestic help with hefty pay packets. Yet they stuck out with the sum of RS. 150/-pm. As they put it - "These are our kids, we cannot abandon them." Were they not depriving their own families of certain necessities, maybe a few luxuries? Their families supported them and stood by them because they believed in their cause. The same sentiment is echoed by Ghansham Bhaiya and Vidyasagar Bhaiya - the two drivers - and Nandlal Bhaiya who works as a carpenter. They give all the credit to their families and despite their pay being low their families have never cribbed, allowing them to pursue their dreams and aspirations. A big thank you to all the families of helpers, drivers and carpenters who may not get the same recognition as teachers and therapists from the outside world. Yet, their families made the same, if not greater adjustments.

It is this commitment to the cause that helps therapists Mansoor, Sudesh, Rohit, Kalicharan, Sandeep and Ranjan to keep going. Sandeep, who is married, stays on the SSNI premises away from his family. Sudesh's wife willingly took a dip in the income and waited patiently for her husband to complete the BDT course to fulfil his dream. I wish she had come to the convocation to see how proud we are of her and her husband. Hats off to all the mothers-in-law who manage the house, or cook and pack hot meals for their daughtersin-law, look after grand children or grand teenagers. Bhawna talks of her tête-à-tête that her mother-in-law and she have every evening over a cup of tea. All joys and sorrows of the day at their respective jobs are discussed. Bhawna proudly told us that it was her father-in-law who had arranged a visit to the ice cream factory for the CSE children. I hope you had a cool time, kids.

"Mom, you are never here" is a statement mothers have to hear constantly. However, kids also say - "Don't worry about me - I will take Crocin. You must not miss school as yours kids will suffer". Duplicate toys, colour pens, books - yes, the kids know where they all go to. Their mother's kids at school. Their families have got used to statements like - "My child, my child's father does not have a job, my child's mother is seriously ill, my child has had a baby brother ??!!"

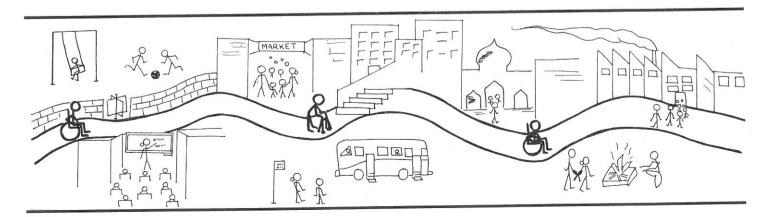
Anita joined SSNI as a volunteer 5 years ago. Today she is an assistant teacher. She comes from a family where daughters are not encouraged to work. Now her father is so proud of her and her work that he feels that she should continue in this line. Smiling shyly she said her fiancé also did not object. In fact, he feels proud of her work. Renu is a special educator at Dayalpur Project near Faridabad. Her home is at Ghaziabad. When I asked her about the support given to her by her family, she thought for some time and then said - "My God, I had never thought about it. It is taken for granted that my husband and brother will drop me at and pick me from the Ashram Chowk at whatever time required so that I can catch the school van. They have adjusted their day so that they can pick me up at odd hours. Both men and my mother-in-law are not demanding and in fact help me around the house quite a lot." When I had spoken to Renu she was being dropped at 5.30 a.m. for a week for a special workshop at Dayalpur.

Rachna Sharma joined as a secretary a month after her marriage. Initially she was very disturbed to see our kids and wanted to resign. It was her husband who told her not to feel upset but appreciate the children and their parents. She is still going strong and is soon going to be the mother of their second child.

Friends also need a big pat on the back - their support comes in various shades - from volunteering at school, to buying SSNI cards to giving donations or sponsorships. Relatives visiting from outside or abroad know their mother, sister, brother, aunt, sister-in-law cannot take off to show them around - well, they accept this and are still proud of us. God bless our extended family for their evergreen support!

Madhumati Bose Staff member

P.S. I wish I could have written about each and every staff member's family, since we appreciate every gesture of solidarity - but lack of space, time and energy prevented me from doing so.



Chanda didi remembers...

When I came to the Spastics Society 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 had 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.

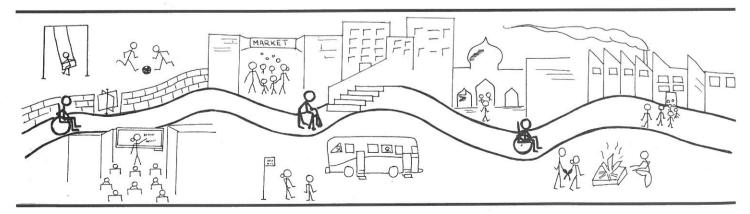
The work was easy then, but it was hard to understand the children's speech. It took a long time, but as I came to know them I started understanding what they wanted. There are some who speak with gestures. Others speak with their eyes.

The school has grown much bigger now, and the children are bigger too, so there is more work and heavier physical labour. I have been here for 18 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.



Our "Chanda didi" who has worked here for 18 years

(As told to Renee Burgard)



A typical day at CSE

And what, you may ask, is a typical day? You have three choices (1) a day when everything, but everything goes wrong, (2) a day when things are partly wrong and mostly right, (3) or a day when everything goes right - when at least one child in the class gives you the correct answer, or a child laughs aloud at a joke you've just cracked. Is it your Hindi, or the joke he's laughing at, you wonder?

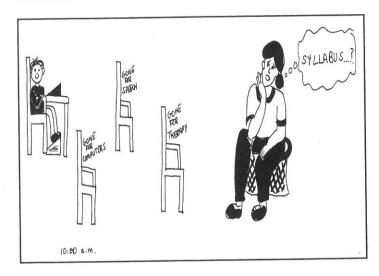
A typical day is a combination of all the above. It begins deceptively enough. It's fairly peaceful upto the gates of SSNI - where the chowkidar may or may not let you in - depends on the kind of night he's had. Then you dash in and the Attendance Register is still there! Oh joy! - Sanjay's watch is slow again! You walk into your classroom - and the room's been dusted, swept and swabbed and - hold your breath - not a cobweb in sight! Can this be true, you wonder again and then you discover, the vans are already here, mobility's begun, and there you are, still in a daze. You run out, grabbing the first available wheelchair along the way but tread softly - the dwindling band of persevering "good" staff members are deep in meditation.



And treading thus - softly - you reach the front entrance and sometimes heart-rending cries can be heard from afar. "He's left my child behind again!" you hear and "How can he do this?" and then a bellow, "Where's ——? Why can he never be found?"

Various under the breath remarks too can be heard. Examples - "Oh! They have grabbed the best wheelchairs again!" or again, "Where's the—helper? He's/She's sitting in the sun, drinking tea again?" - followed by a loud though plaintive cry of "Sister Linda - I must tell you - ——" And so it goes on.

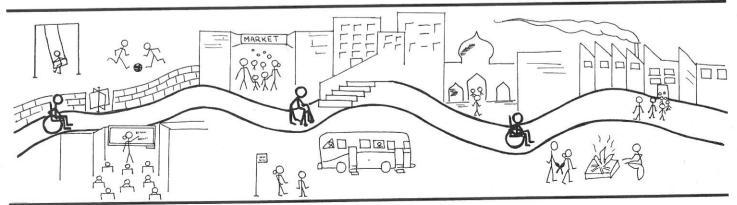
After the hazards of the morning have been safely countered, you've reached your class again. No mishaps along the way, except that the wheelchair screeched horribly, jarring on already tender nerves, but never mind, your child's safe. The prayers have been said, your precious volunteer has arrived (bless her) no one has yet stolen either your chair or hers - and you take a deep breath and try to begin your first class.



Try, I said. You can try - but in walks Bahadur, paper in hand - sign here, sign there - news of yet another meeting - and groan - another long day!Oh well! you say - and try to start again. This time its the therapist. Quite chirpy, as they all are. "Standing time", he calls out or "Therapy" - and there, half your class has vanished. Before they get back to you again - they disappear, this time into the computer class. Visions of various syllabi flash warning signals before your eyes, but valiantly you ignore them.

Tea break, next - only there's no break andwhat comes around in the ancient kettle is not easily identifiable as tea. It could be anything, in liquid form. Stretch your imagination a bit, and yes, in some distant past, it had had some vague connection with the weakest tea bush.

Then it's lunch time, toiletting, teeth brushing. You heave a sigh of relief, your stomach sending out frantic cries

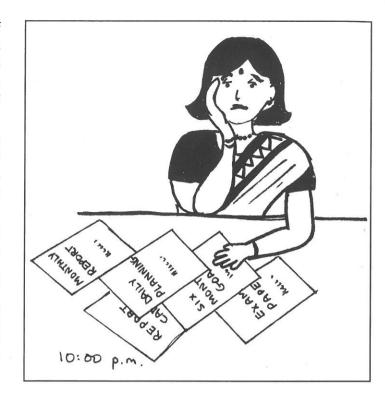


of distress. You meet in the "staff room" - no chairs again of course, they've disappeared without a trace. You lunch, with various enthusiastic people holding forth. - "Shop talk" its called, sort of like mini meetings. You eat another's lunch, never mind hygiene, and before you know it, it's time for class again.

And of course you'd forgotten - it's not a teaching class silly, it's gross motor time. So off you go again, to the old lobby, where countless feet have trekked in inches of dust. You gross motor on, regardless, till breathless therapists rush in to remind you that it's going home time.

The vans leave (they didn't need a push start, for once) belching out super graphic designs of diesel smoke in interesting shades of dark grey and black - and every child, helper and driver is safely in. You heave another sigh of relief, smile at nearby friends, gather together to joke or crib, as the mood dictates - when suddenly you realise - you've forgotten to write the homework in the diaries and horror of all horrors - some child's bag and bottle has got left behind again!

Exhausted, nerves stretched by this your normal, typical day in CSE, you trail homewards - your head pounding to the rhythm of MONTHLY REPORTS MUST BE IN BY TOMORROW—

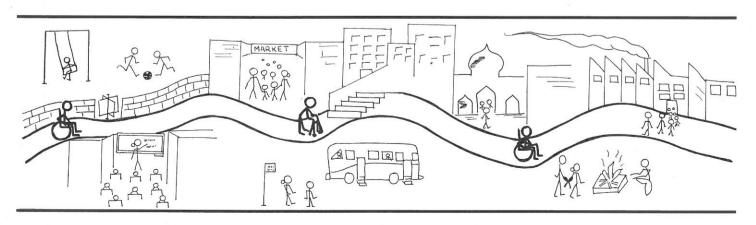


And, you wonder.....! Of course, with great love and affection, regardless of all that comes your way, every day.

Beera Mitra (Illustrations by Kanwal Singh) Staff members

You give but little
when you give
of your possessions.
It is when
you give of yourself
that you truly give.

Kahlil Gibran



Evergreen memories

Two organisations with which I am very closely linked - SSNI and Kalpavriksh (an Environmental Action Group) - share a very special significance in the year 1998. Both celebrate 20 years of their existence. Hence, when asked to write for the special anniversary issue of SSNIPPETS, I cannot help but recall, among the many special moments of work at SSNI, the period where I felt a merging of my concerns for disability and the environment.

I joined Kalpavriksh (KV) in 1984 when I was a post-graduate student of Delhi University. Coming from very protected college environments in the South, where we busied ourselves with intra-college activities and rarely looked beyond, KV experiences (slide shows, nature walks, bird counts, protest marches) kindled a sensitivity in me towards environmental issues.

In 1987, I joined SSNI as a student of the TTC course and have been a staff member since then. My early years of work in the academic section of CSE have left me with many indelible memories. In my second year of work, KV members helped us to organise a trip to Corbett National Park and a few years later, another visit to Chilla, a part of Rajaji National

Park, also in UP. At Corbett, we were lucky to spot a tiger (the forest officials told us that they were very elusive at that time of the year). At Chilla, we saw a chital suckling its young (a very rare sight again, according to the wildlife warden). My atheism started wearing thin - somebody up there was looking after us!

SSNI lent its support in a small way to the Narmada Bachao Andolan. Oustees from some submerged villages in Maharashtra organised a dharna at Rajghat. The families had lost the precious little that they owned. Some of our students visited the dharna site one morning and had the opportunity to meet Baba Amte. Issues like submergence, displacement, loss of livelihood etc. were alien to the students, who were able to familiarise themselves with these issues during a lively question and answer session with the oustees. When we were ready to leave, some of the villagers thanked us warmly for our support. They said that even though they had lost all their possessions, they felt that being able to walk without difficulty was a blessing that they still had. As we left in our van, Mithun echoed the feelings of the group when he said, "I may be disabled but at least my home has not

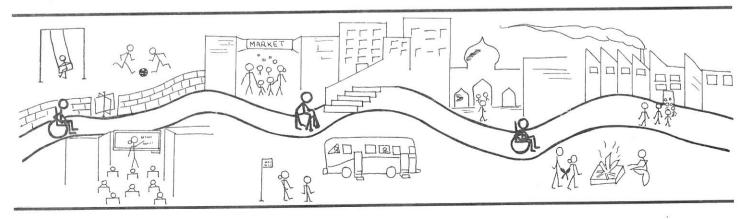
been washed away." Solace, but at what a price!

To KV and to SSNI, I owe a lot. I have met innumerable people whose many acts of kindness and concern have been a source of inspiration and whose commitment to a more just and equitable society has been unshakeable. These organisations have played a tremendous role in sensitising many people towards the disabled and the state of our environment. In a world that is getting increasingly hurried and seems to be shutting itself off from the larger questions that concern mankind, I feel that these two organisations have played a wonderful role in reminding us of who and what we really are.



Three CSE students participate in the school children's march to save the Delhi ridge in Feb '94

Sujatha Padmanabhan Staff member



Looking ahead...

The Spastics Society of Northern India, or SSNI as we all fondly call 'her', today stands tall in the field of disability work. From being a specialist institution working with people who have Cerebral Palsy and multiple handicaps, the place has become a model for integrated delivery of services combining tertiary level care with community-based rehabilitation. In a country where disability issues have low priority, it is not easy to meet the objective of quality standards while reaching out to large numbers. In the course of my career involving networking with organisations caring for people with disabilities, I have observed that SSNI is in a class above the rest. It is not merely because of its size or by virtue of its being an early entrant to the field. While there can be no denying that entering the field early for work in disability gave the Centre a certain advantage, SSNI has proved beyond doubt that lack of funds cannot be a constraint for good work and that it always pays to be sincere and persevering.

My association with the Society (for over a decade now) has given me valuable insights into the commendable work done here and inspired me to gradually change my practice of Paediatric medicine in its standard form to the current one in which the focus is on developmental disabilities of childhood. I am not alone when it comes to people being influenced by SSNI's magnetic personality and dedication. A major strength of SSNI has been its ability to motivate volunteers and experts to give their best. Today SSNI has

come of age and is ready to shoulder greater responsibilities. There is an increasing realisation that education, welfare, rehabilitation, health, economic issues are all inter-related in the integrated care of the community and disability is but an issue in this integrated whole.

While it is true that SSNI cannot ignore other issues, she cannot afford to forget that, as an organisation of stature in providing specialist services for the disabled and as a training centre for professionals caring for persons with disability, excellent standards of rehabilitation for the neurodevelopmentally handicapped are expected from her.

One role I would like SSNI to take on is that of helping set up smaller centres for similar services in different parts of North India (apart from consolidating the Dayalpur section) and to train manpower from the local community to make these centres independent .

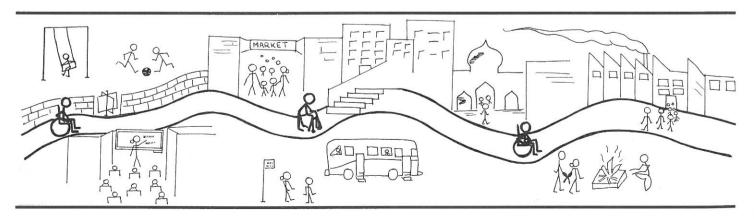
As SSNI takes on the challenge of ensuring that people's needs are optimally met through a wider set of services, a critical issue will be the maintenance of adequate technical standards while reaching out to larger numbers with the same sense of dedication and character that has become its hallmark. I, for one, am certain that SSNI can rise up to the challenge and wish the organisation all the best as she enters her twenty-first year!

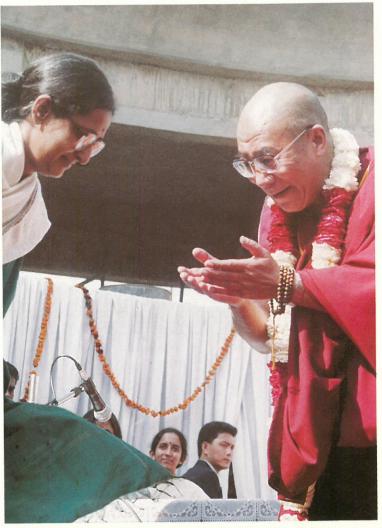
Dr. SunandaConsultant

There is light

If I cannot have the sun,
I still have the moon.
If I cannot have the moon,
I still have the stars.
If I cannot have the stars,
I still have the evening lamp to give me light.
If I cannot have all these,
I go to sleep and dream there is light.

Manish Gupta Student



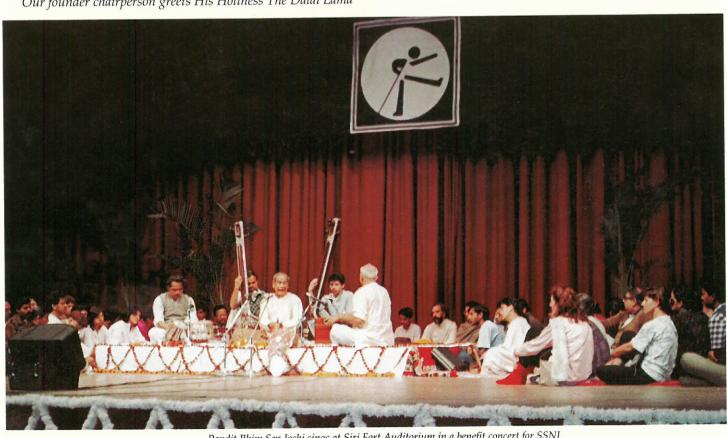


Our founder chairperson greets His Holiness The Dalai Lama



An exercise of solidarity during our vision mission workshop

A peep into the past



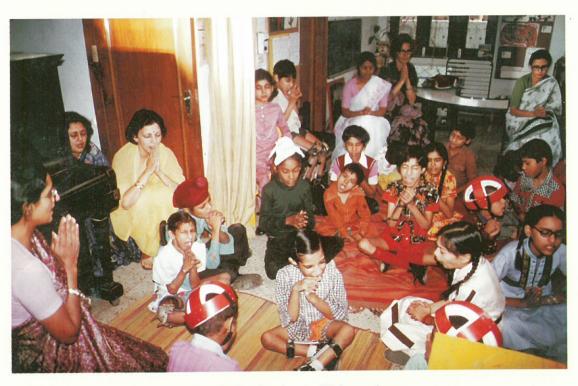
Pandit Bhim Sen Joshi sings at Siri Fort Auditorium in a benefit concert for SSNI 9



A class in progress in our rural CBR project.



The first batch (1984 - 85) of TTC students receive their diplomas



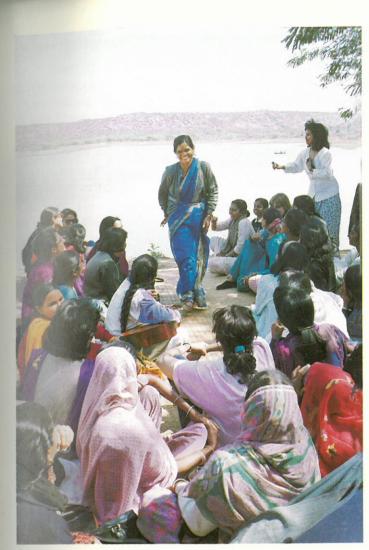
Prayer time in our SDA premises.



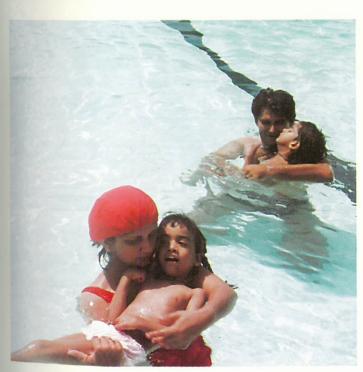
At our HM project - breaking the ice



VWTC trainees learn to block print with vegetable dyes at a special workshop organised at Sewapuri



Staff picnic - an annual fun event



Swimming at Talkatora - always a special treat!



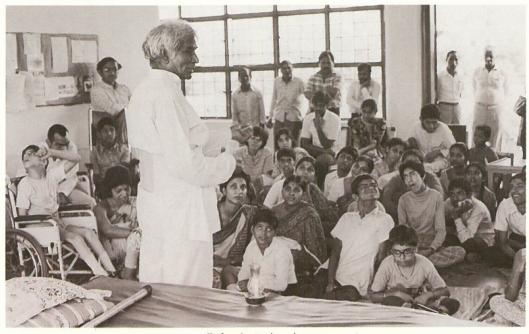
CSE students make new friends at Corbett National Park!



Staff let their hair down - to entertain students on Children's Day



" Our weekly assemblies are great fun and help us build our confidence"



Baba Amte inspires us



Raising awareness of the problems of wheelchair users through a simulated exercise



Access to public places - still a very big challenge.



Disability rights activism 12

Lighter moments with Mita

The old school at Safdarjung Development Area had been lying empty for three to four years. Since I lived in the same colony, I knew it as the Bhoot ghar (ghost house) . News filtered round that someone had rented that place. I couldn't believe it! Someone was in a desperate situation to have moved into that house! When I passed by the house one evening, I saw the "Centre for special Education" Board at the rather ramshackled gate. I was teaching at Loreto Convent at that time and little did I know that I would also be a part of this house. There had been some untimely deaths in this place and people had seen spirits hovering around at night! Nar Bahadur was our chowkidar and swore that he saw the spirits in the day time too!!! After telling us some really strange stories, he finally declared, one day, that he and the spirits were friends at last !! Obviously, we were not part of that sublime friendship. The last room had a pelmet with a rather attractive curtain. It was known to fall on staff members sitting below it - many a staff saw stars in the day time and most of us steered clear of that pelmet! Nar Bahadur's explanation was that the spirits hung their clothes on it since we had used up all the cupboard space! Some consolation! And then, one afternoon, during school hours, three of our tape-recorders disappeared. You're right! The spirits needed some music in their lives!!

One morning, while we were waiting to start assembly in the old school , there was a sudden 'shower' on us—littered on the floor were egg shells, cabbages and smelly stale food! We had heard of "manna from Heaven" but this was unbelievable!! We were about to blame the spirits when one colleague looked up and saw the spirit in flesh and blood! Before we could yell, down came another shower of garbage. It was the landlady's wrath at not receiving her monthly rent in time! Till we would know that the rent had been paid, we would run the gauntlet every morning! During that crucial first week, Mita had to be hidden in the toilet to save her form the landlady's anger and Mita would stay there till she would get the signal to emerge! Funds were so difficult to get at that time.

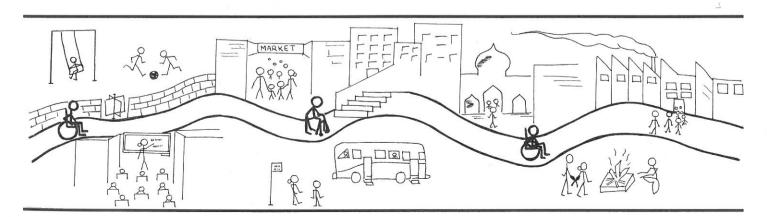
A good samaritan had donated us a colorful swing for the children. Mita had noticed adults screaming with delight with every 'swing'!! Soon a stricture was put on the use of the swings by staff and helpers. I would look longingly at the swings, and then one day, the temptation was too strong to resist! My colleague and I decided to 'swing it' during the break. What joy! Childhood days were back again! And then, in walked Mita through the gate. With the swiftness of an eel, my colleague slid out of the swing. I've never forgiven her for this! I swung into action, too, but found to my horror that I was stuck! Sudden realization set in— "seat size" matters. Mita's look and the silence while I struggled to get myself out was so embarrassing that I never 'swung'again!

Mita was rather pensive one day . Some of us had told her that when there were too many female employees in an organization, they tend to gets on one anothers' nerves after some time !! A diversion in the form of male employees was desirable . And if they were presentable and handsome, that would help ! One day, while I was in class, Mita walked in, and with an amused expression said, 'Vinita, please meet our new physiotherapist , Khusroo!' I was speechless! Where did Mita find him — this delightfully handsome man !! I smiled back at Mita, and then life was not the same that year. I often wondered why so many of the young ones had such frequent aches and pains to be attended to by Khusroo!!

We had weekly detailed analysis of the progress of the children in classes IX and X of the C.B.S.E stream. Every topic was covered in detail with Mita. We had an eager, young and dedicated graduate who taught chemistry. He needed guidance and as a supervisor I kept in close touch with him. At one such meeting, there was some doubt about the completion of a particular topic in chemistry. Mita asked , "Has this been completed?" There was a pause and some stammering, which prompted Mita to ask, "Did you or didn't you?" Pat came the reply, "yes."

I knew I was next in the line of fire !! Looking at me Mita asked, "What does he mean by yes?" I was puzzled myself with the yes, so asked Mita if I could go out and clarify. Once outside, I asked him, "why are you saying yes, it means nothing!"

Looking exasperated, he replied," why does Mita didi



ask two questions at the same time? 'Did you or didn't you'? I come from a Hindi medium background and I get confused." I got back to Mita with this feed-back. The following week we had another meeting. Mita forgot and asked him again, "Did you or didn't you?" Pat came the reply 'yes and no!!'

The school was in its infancy. Mita had funds to raise to pay the salaries and the monthly rent, organize training programmes, meet government officials for futher help. Her work was round the clock. She had literally no time for herself. On one of those days, she was rushing out of the gate and then remarked, "I'II have to find time to get my eyes tested. One of them has definitely deteriorated. "That's when we noticed that one of her lenses had fallen off somewhere!! Was Mita relieved!! She was off to complete her mission.

Vinita Rawat Staff member

Worlds apart

Having worked for four decades in the rough and tough world of military life, I walked one day after retirement, into the totally different world of SSNI.

Firstly, I had never seen so many women in my life, leave alone worked with them; and in keeping with what I had been taught in the defence forces, I would spring to my feet every time a lady walked into my office. I soon became a sensation, and I suspect even young volunteers would walk in to see the jack-in-the box jump up each time they entered. Minu di however soon put a stop to my oscillations by quickly sliding into a chair before I would get up and later on convincing me that getting up was just not necessary.

I was a little perplexed at first, at the lack of response to punctuality, and the way things generally worked. In the army, an order evoked an immediate response. Here, things took their own time. I soon realised that at SSNI, responses were linked with conviction. Things worked provided you carried everyone with you — a fundamental principle of leadership and management. I realised that discipline in the world of disability was of a different kind In the army, one never ate till the jawans had eaten. Here, not only that, we serve and feed our childen as well, and also do much more than that.

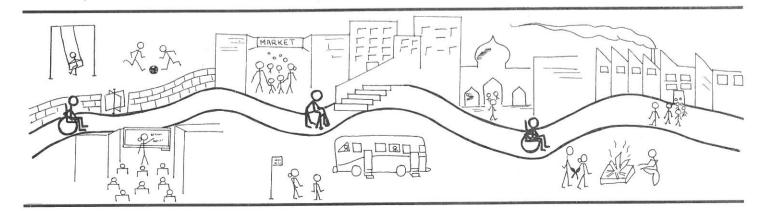
Previously, my day resounded to the staccato sounds of gunfire on the range and the crash of boots on floors, of

pipes and drums, bugles and trumpets, of the hoofbeat of horses and the clash of arms. The change at SSNI was very dramatic — the soothing sounds of bhajans, the tinkle of laughter as staff greeted each other, the cries of joy as the vans arrived at school, the soft cadence of children repeating their nursery rhymes and the rustle of the magnificient pink cassia outside my window was a refreshing change.

Compared to the harsh world of violence that a soldier faces in his daily life — this was a softer world — a world of caring. However, although everyone is loving and kind in our society it has a blend of toughness; and the steel shows when the occasion demands. There has never been a compromise on principles and our unshakeable priority remains the multi-disabled over everything else.

Work at SSNI moves at it's own relentless pace. The needs of our disabled is such that there is rarely a moment to relax. Cranked in however with our frenetic activity is the message of the most important thing in the world — the message of love. I have learned a lot at SSNI and I have a lot more to learn. I am convinced however that I would have been a far better officer had I spent some time at SSNI before I joined the army.

Ian Cardozo
Staff member



Exam blues

Examination fever was at its pitch in Delhi and in greater intensity in our class Xth CBSE classroom. Amrit Pal Singh was struggling to keep his wits about him - the exams were looming over him like a dinosaur! The month was January and so close to the horrifying spectacle of an examination. I had put a curfew on his outings, no music system blaring away till midnight at home, no long conversations on the telephone and no day - dreaming! Cynically, he once queried if he could breathe! Amrit had joined school when he was eight years old and within eight years of education he was ready for the Board exams. I had requested Mita didi to be the proverbial "dragon." Everytime I thought I was losing my hold on Amrit, I'd send him off to Mita didi for an eye-to-eye contact (a counselling cum lecturing session) at which Mita didi excelled! She hated this role but I had convinced her that there had to be one "super - dragon" around - the ultimate terrifier!

On one occasion just when I threatened to send Amrit to Mita didi, while he was going down the stairs, ever so gracefully and in slow motion, he went into a faint. I would have died of guilt at that moment and yet I knew that he had not put in even half the hours of study as compared to his counterparts. So the question of "burning out" did not arise.

I ran to Mita didi for help. Tiptoeing, she went to Amrit, bent down and observed him closely. Smiling, she came back to me. "He's shamming," she said, and then in a matter-of-fact tone asked me to get the van to take him to AIIMS. The effect was instantaneous. Amrit squirmed, opened his eyes, dramatically and Bollywood style, whispered "Where am I?"

He never repeated this stunt again because, in any case, he was marched off to Mita didi's office!!

Vinita Rawat Staff member

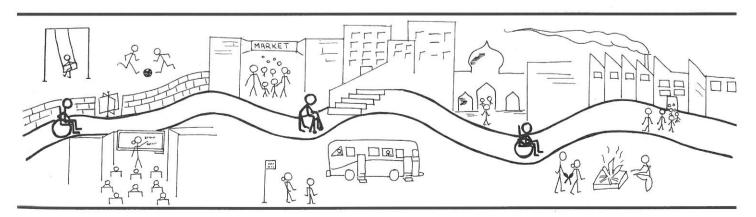
Just let the steam out

I am Samuel Mani, 22 years old. I am doing BCom Pass, III Year from Shaheed Bhagat Singh College. Up to Class X, I got a lot of support from my teachers and therapists at SSNI which continued in St. Mary's School from where I passed CLASS XII. I naturally was looking forward to an enjoyable college life like my cousins and friends. But the bubble was broken when I had to obtain a disability certificate, which was necessary for admission in a good college despite having 69% marks. The admission process was so difficult that it came as a big jolt to my self-confidence.

Travelling up and down to college is another struggle every day since the auto men charge exorbitantly when they see me in a wheelchair. Despite these odds I have been lucky to make good friends at college. I have started giving computer training to children with the help of my computer teacher.

I often wonder what gives me the strength to carry on despite so many negative forces working in the environment. One thing that my uncle told me long back always helps - I sit and talk to myself and let the steam out. After that I don't think about it again.

Samuel Mani Ex-student, SSNI



A touch of gold

My name is Vidya Sagar Nehra and at 88+ I am perhaps the oldest retired engineer officer of the Indian Army and the oldest volunteer at SSNI, the Spastics Society of Northern India, an organisation I have been associated with for the past 9 years.

My work here at the Vocational Work Training Centre, has introduced me to young persons being assisted to learn to value the dignity of labour and become self reliant citizens. In my own way I believe I am contributing to this cause as I arrange work tables, support a hand, push a wheelchair, tell a story, play chess or listen to a young friend who is in need of company. These and others are simple tasks..... but I know my effort relieves someone else to take on other jobs that have to be done. And from what I have seen , there is always more than enough work for all of us.

As a volunteer I am prepared to do anything that needs doing. Why am I a volunteer?

Perhaps this helps me cope with my helplessness at what I see on the street and can't do much about. Perhaps it is an inner urge to live what I have learnt from my parents...that it is better to give, without any expectations..than to take from others and that is my way of

contributing to the community. Perhaps it is merely to keep myself busy....to satisfy myself... if I don't keep going I know I am finished, I would be another old person grumbling about his aches and pains and loneliness and living in the past. Yes, volunteering is selfish.

There have been many pay offs for me. The young people I meet, the new learning and my growing sensitivity as I face people who give me a purpose in life while they struggle to find one in theirs. To them I owe deep gratitude.

It is tough at times...I am not as energetic as I used to be, my back hurts when I walk, but the urge to share what I have persists.

The question is whether we want to contribute to our community while satisfying ourselves. If you want to, then you will find a way of sharing the many resources you have, as a housewife, professional or student. Nothing can stop you, least of all old age!

Colonel Nehra (This is col. Nehra's address at one of our fund raising events)

We are not now that strength which in old days

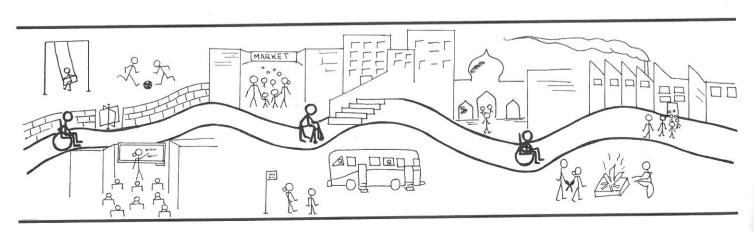
Moved earth and heaven, that which we are, we are,

One equal temper of heroic hearts,

Made weak by time and fate, but strong in will

To strive, to seek, to find, and not to yield.

Tennyson



To Let

Small to very large, comfortable, half furnished single rooms available in posh, South Delhi Colony, next to highly fashionable neighbours. Rooms housed in large womb-shaped red building resembling Shah Jahan's Red Fort.

Rent: Not negotiable, according to policy.

Perks:

- Telephone facility, official calls free of cost, and can even be received on Sunday nap-times.
- Free solar energy available within rooms in summer months to boil eggs!
- Variety of professional skills available at door-step carpenter, physio-therapist, plumber, electrician, driver.

Added attractions:

- Skill enhancement possibilities late night visits to hospitals, nocturnal counselling sessions and a wide range of crisis management situations
- Heightened satisfaction through frequent opportunities for blood donation
- 24-hour work opportunities to suit all degrees of workaholics.

Qualities of tenants:

• Essential:

Spinsters or bachelors (preferably the latter)
Height, complexion no bar
Capacity to work elastic
Highly adjustable
Stamina to scale 3 flights

• Desirable:

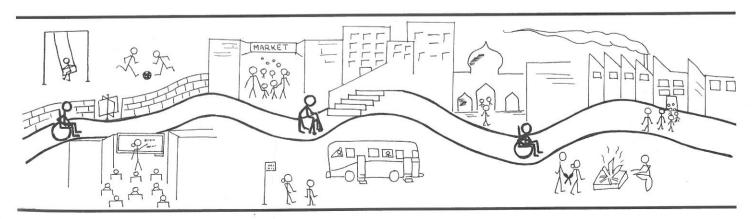
Concern for natural resources to facilitate switching off lights in basement, or close tap in all bathrooms on all floors

Tremendous grit to unearth 'CAPART guidelines' well past dinner-time to be sent to all GB members Large heartedness - to supply tea, biscuits, crockery, salwars etc. as and when required Florence Nightingale like qualities to give unconditionally at all times in all ways

Apply to:

'Living on the Edge' Co-ordination Committee Top Floor, Red Building No. 2, Balbir Saxena Marg Hauz Khas, New Delhi

Ph: 6966331 (office cum residence)



So much to learn...

I wonder who learns and from whom and where and how...! I was working as a Faculty Member at the National Open School when I happened to meet two very dynamic young ladies who wanted some help for their young learners. The learners were from the SSNI and were specially challenged. I was astounded to learn of the extent of the disabilities of these young people. The will to overcome their disobedient limbs and get on with the business of normal living was evident in the way they worked - with total concentration and dedication to the task at hand. It was then that I came to realise how motivation to do something could lead to discovering ways and means of achieving the same. I just had to come to meet these young people who were ready to take on the world, on their own terms! They were working against all odds, making their disobedient limbs listen to them. It was an eye opener for me to see such grit and determination in people so young. I wanted to do all I could to help them in their struggle to overcome the unfair deal they had got in life. And then began my crusade within my organisation to see that learners with such challenges were given due concessions regarding the practical work in subjects chosen, time allotted during examinations, help of

a trained writer during examinations, etc. It did indeed feel good to be part of the organisation which brings education to the doorstep of those who cannot go to a school but it was not enough. The bright and eager faces of Pankaj, Namit, Mithun and others prompted me to do something more. It was then that an idea emerged that perhaps NOS could devise some courses, which were not very exhaustive but were just sufficient to impart practical life skills to these young learners. As a result of a seminar organised at the national level, many ideas were received. Work has been initiated and very soon we hope to introduce very shortterm courses on functional mathematics, functional literacy, some vocational courses which need simple, repetitive skills, etc. We, at NOS, hope that we will be able to come up with more such need based courses for our special learners. One of the most important things that I personally have learnt is that nothing in this world is impossible if only one has the will to do it!

> Sandhya Kumar (Faculty Member National Open School)

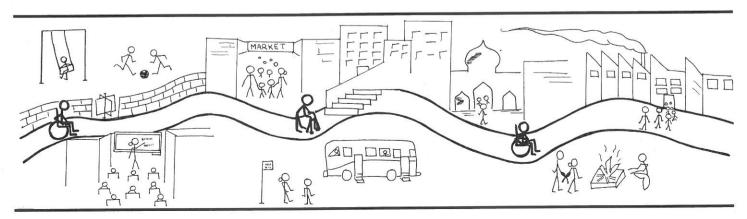
SUNRISE

You sit inside your wheelchair And watch the world pass by From under shielded eyes... A flower waiting for a sunrise

Then a smile dawns into your life And touches you with love You escape the chrysalis - shell... A butterfly of joy and promise The sun has risen.

Now you know There is no need to walk When you can fly...

> Br. Deasy Consultant



Reach for the sky

" A cloud does not know why it moves in just such a direction and at such a pace. It feels an impulsion...this is the place to go now. But the sky knows the reasons and the patterns behind all clouds, and you will know too when you lift yourself high enough to see beyond the horizon."

Richard Bach

For all who joined the TTC course, the reasons were many... and different. But for all it was a very conscious choice. A choice made in the face of the numerous options available in the world around. Yet a choice made on an impulse from within - without knowing the full extent of what it meant to work with children with disabilities.

And today, it is a feeling of 'coming home', of 'belonging.' Which emanates from both the physical environs of the cheery red brick building and green trees to the warm and welcoming smiles on the faces of all the SSNI members.

Its given a meaning and direction to many. Has made some of us realise undiscovered strengths and potentials within - and importantly has made us feel good about ourselves.

There is such a strong current of commitment and dedication that it is impossible to not get affected by it. For, most of us it is a new world, a different world - a world where there is so much to discover and learn. One in which we know that we as people will grow as never imagined.

The learning is not easy. From the integrated technical aspects of special education to the wider understanding of development - it is a surfeit of knowledge. But it is extremely well structured and co-ordinated, and the whole process is one of sharing and learning.

And then as Richard Bach says "You are never given a wish without also being given the power to make it true You may have to work for it however"

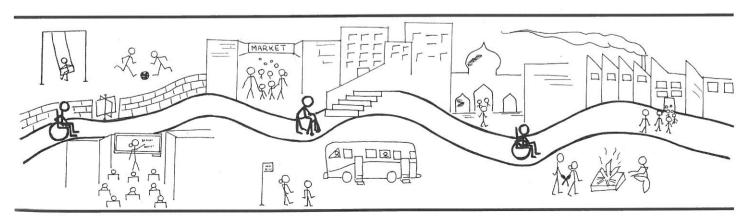
The TTC class 1998-99

BEYOND WORDS

Any living being needs to be looked after and helped by others at different stages to grow. This Society, which I call my extended family, identified my little strengths and gave me the opportunity to grow, blossom, build and sustain myself. It has given a different meaning and purpose to my life.

It is not only I, but even my family that has gained indirectly from here. In times of personal need, everybody supported me to the fullest. It was Mita who opted to consider my case for admission to the TTC course as well as for a job. Mita has a keen eye to see a spark anywhere. I do not have words enough for this place and even if I do not like something, I feel that it is a part of it and not the only thing.

Sanyukta Kumar Staff member



माँ के उद्गार

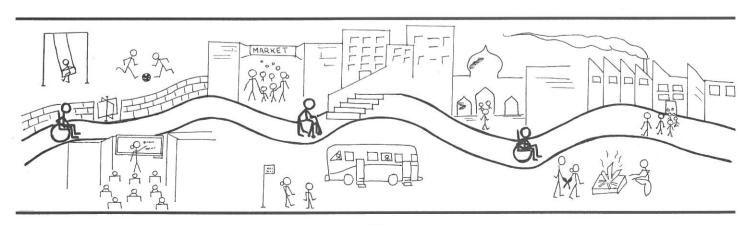
मैं श्रीमती करुणा कुमार, दो बेबिओं, सोनल 19 साल और नूपुर 17 साल की माँ हूँ। सोनल के जन्म के साथ खुशियों का भरा पूरा संसार था, परंतु किन किठनाइयों का आगे सामना करना पड़ेगा इसका दूर तक आभास नहीं था। नूपुर की स्थिति का पता चलने पर थोड़ी घबराहट तो हुई पर अपने आप को कभी लाचार नहीं माना और मन से कभी हार नहीं मानी। इस सब में सहारा बने मेरे पित, मेरे मित्र, कुछ संबंधी और यह जगह जहाँ मैं आज खड़ी हूँ एस. एस. एन आई। बच्चों की समुचित व्यवस्था यहीं से शुरू हुई। यहाँ से निकलने के बाद अब बच्चे श्रीमती शुभ्रा मुखर्जी के सेंटर उड़ान में जाते हैं। वहाँ भेजकर मुझे लगता है कि मैं हर समय बच्चों के साथ हूँ।

ईश्वर सभी की ऐसी परीक्षा नहीं लेता एच. सी. पी. ए. फाउंडर प्रेसीडेंट श्रीमती सतवंत कौर हमेशा कहा करती थीं कि कुछ विशेषता देखकर ही ईश्वर ने हमपर यह उत्तरदायित्व डाला है। समय समय पर समस्याएँ आती हैं, कष्ट भी होता है और विपत्ति के कठिन क्षणों में पीड़ा के माथे पर ही आनंद तिलक चढ़ता आया है। पर एक विशेष खुशी, प्यार, लगाव, मान-सम्मान जो यह बच्चे हमें देते हैं वह दुनिया की कोई चीज़ नहीं दे सकती है। घर में कभी नीरसता का वातावरण नहीं आने दिया। चेहरे पर विषाद की कभी एक भी रेखा नहीं आने दी। ऐसा कर पाना किसी आन्तरिक शक्ति द्वारा ही सम्भव हुआ। मेरी आँखों में भी एक माँ की व्यथा थी परन्तु ईश्वर सब दरवाज़े एक साथ बंद नही करता कुछ प्रेरणा स्त्रोतों के सहारे हम अपना जीवन सरलता से काट सकते हैं।

श्रीमती करुणा कुमार



I shall pass through this world but once
Any good therefore that I can do,
or any kindness that I can show to any human being,
let me do it now.
Let me not defer nor neglect
for I shall not pass this way again.



एस. एस. एन. आई. की बीसवीं वर्षगाँठ

प्रत्येक संस्था के लिए कुछ अवसर तथा दिन ऐतिहासिक होते हैं। उनके बीत जाने के बाद वही यादें और क्षण यादगार बन कर रह जाते हैं। ऐसा ही एक अवसर हमारी संस्था एस. एस. एन. आई. में भी आया। 14th नवम्बर 1998 को हमारी संस्था को आरम्भ हुये बीस वर्ष पूरे हुये। यह अपने आप में एक बहुत बड़ी उपलब्धि थी। मीता दीदी ने जिस पौधे को लगाया था उसने अब एक वृक्ष का रूप ले लिया। हम सभी की इच्छा थी कि हमारे विद्यार्थी, उनके अभिभावक, हमारे स्वयं सेवक तथा ऐसे बहुत से स्कूल जहाँ हमारे बच्चों का एकीकरण हुआ है, सभी मिलकर फाउंडर्स-डे को मनायें।

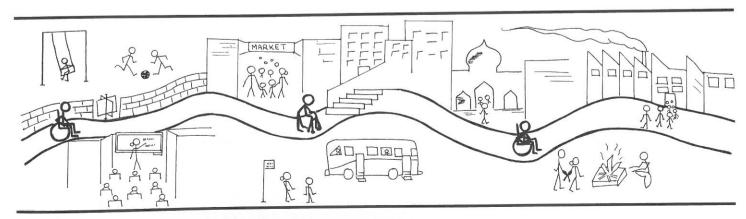
14th नवम्बर के दिन हमारे विद्यालय में सांस्कृतिक कार्यक्रम का आयोजन किया गया। कार्यक्रम के लिए निमंत्रण-पत्र भेजने का बीड़ा वी. डब्ल्यू. टी. सी. विभाग ने उठाया। उस दिन लागों ने जैसे ही स्वागत-कक्ष में प्रवेश किया, वहाँ एक हलचल सी महसूस की। सामने एक बड़ा सा वृक्ष बनाया गया था जिस पर हर आगंतुक अपने अँगूठे की रंगीन छाप लगा कर यह बता रहा था कि वह एस. एस. एन. आई. से क्यों जुड़ा है। सांस्कृतिक कार्यक्रम विद्यालय के खुले आंगन में सुबह 10 बजे आरम्भ हुआ। बैठने का प्रबन्ध होम मैनेजमेन्ट विभाग द्वारा किया गया था। हमारे एस. आर. एस. के विद्यार्थी, बच्चों एवं अतिथियों को बैठाने के लिए तत्पर खड़े थे। विद्यालय के बोर्ड पर चित्र लगाने, लिखने आदि में भी उन्होंने अपना योगदान दिया।

कार्यक्रम का आरम्भ श्री बी. डी. चौधरी के निर्देशन में प्रकृति तथा सर्वभूत जगत में शांति की कामना करते हुऐ कॉयर ग्रुप के श्लोकों से हुआ। सारा वातावरण संगीत के स्वरों गुंजित हो गया। ऐसा ही कुछ प्रयत्न मयूर विहार के एक्टिविटी सेंटर द्वारा भी किया गया। तत्पश्चात हमारी चेयर पर्सन श्रीमती दिव्या जलान ने बहुत ही अनौपचारिक रीति से एस. एस. एन. आई. के जन्म से लेकर आज तक का लेखा-जोखा दर्शकों को सुनाया। उसके बाद जब पर्दा हटा तो दर्शकों के सामने था जंगल का एक अद्भुत दृश्य, जिसमें एक ओर थे खूँखार जानवर और पीछे पंक्ति में बच्चे हरे-भरे वृक्ष बनकर मस्ती में झूम रहे थे। यह था हमारा नाटक 'याहू! जंगल में मंगल' जो एस. एस. एन. आई. स्टाफ द्वारा ही लिखित, निर्मित एवं निर्देशित था। इसमें हमारे बच्चों का साथ दे रहे थे 'फादर एग्नल स्कूल' के तीसरी कक्षा के बच्चे। एकीकरण की ओर यह हमारा एक ठोस रचनात्मक कदम था। इसी विचारधारा को दयालपुर पुनर्वास केन्द्र के बच्चों तथा दयालपुर के कुछ सरकारी सामान्य स्कूल के बच्चों ने मिलकर अपने नाटक 'दास्तांने कुदरत' द्वारा आगे बढ़ाया। इस बार बच्चों के अभिभावक भी नाच गाने में पीछे न रहे। पंजाबी लोक-नृत्य की तैयारी कई दिनों से चल रही थी। मंच पर जब नृत्य आरम्भ हुआ तो रंग ही बदल गया। गिद्दे की लय पर सभी दर्शक ताली बजाकर झूम रहे थे। कार्यक्रम के अंत में कुछ पुराने विद्यार्थियों तथा माता-पिता ने मिलकर अपने अनुभव दर्शकों के साथ बाँटे कि किस प्रकार उन्होंने जिंदगी की लड़ाई लड़ी और परिस्थितियों का सामना किया। इस आदान प्रदान में कुछ के घाव हरे हो गये और आँखें भी भर आई।

जहाँ एक तरफ सांस्कृतिक कार्यक्रम समाप्त हुआ वहीं दूसरी ओर होम मैनेजमेन्ट का स्टाफ ट्रे लेकर पेट पूजा कराने के लिए तैयार खड़ा था। एस. आर. एस. के विद्यार्थी भी इस कार्य में उनका हाथ बँटा रहे थे। गरम-गरम चाय सबका इन्तजार कर रही थी।

वैसे तो हम सबके दिल भरे हुये थे क्योंकि हमारी अपनी मीता दीदी गम्भीर रूप से बीमार थीं, परन्तु उन्हीं की इच्छा के अनुसार सारा कार्यक्रम हँसते-खेलते पूरा किया गया।

> रूपा, रंजना, सुलोचना सह-कर्मचारी





Acknowledgements

This publication would never have been possible but for the enormous support we have received from many individuals.

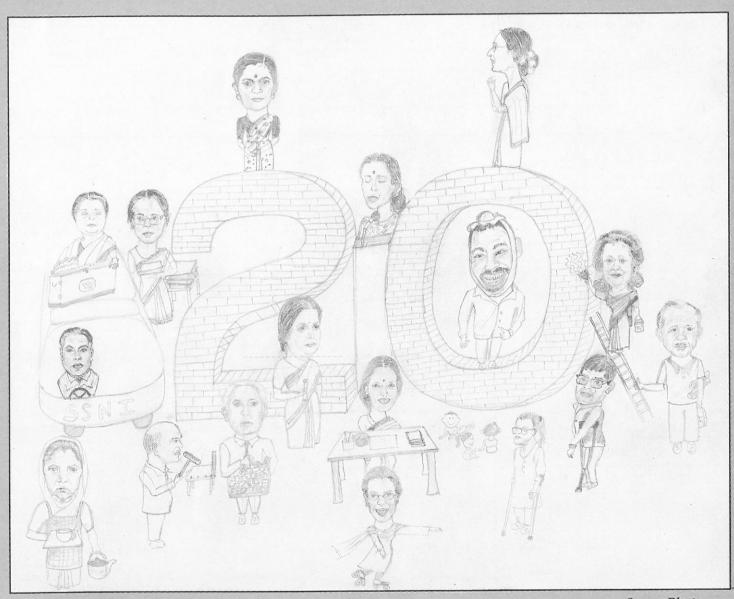
We specially thank:

all at **Surya Print Process Pvt. Ltd.**, who have given us this publication free, and have spared no effort in helping us with the layout, design and page setting

Neena Jindal, who gave her time generously to design the covers

Sakshi Broota and Kanwal Singh for the strip design.

Photographs: Renee Burgard, Jyoti Suri, Ashish Kothari.



Seema Bhatnagar SRS Student

Ah, but a man's reach should exceed his grasp or what's a heaven for.

-Browning





The Spastics Society of Northern India

Balbir Saxena Marg, Hauz Khas New Delhi - 110 016 Tel : 656 9107, 686 4714