

If something comes to life in others
because of you,



Then you have made an approach
to immortality

Norman Cousins

असतोमा सद्गमय ।
तमसोमा ज्योतिर् गमय ।
मृत्योर्मांमृतं गमय ॥
ॐ शान्तिः शान्तिः शान्तिः ॥

asatomā sadgamaya
tamasomā jyotir gamaya
mrityormāamritam gamaya
Om śhānti śhānti śhāntiḥ

SSNI/AADI

Early Years under the leadership of Mrs. Mita Nundy

Persons with childhood and life-long disabilities had no access to the outside world in India in the early 70s. For many of us who now see people with disabilities, supported by legislations favoring their rights, fighting for equal opportunities for admission in regular schools, universities, jobs, entertainment and access to other routine services, it might be difficult to imagine how it was back then. Things have changed. Looking closely at the most challenging condition within the area of disability in which multiple functions are impacted, it has been the pioneering efforts of a young mother in the early 70s that has been the force behind the change. Mithu Alur moved beyond her challenging personal experience with her daughter Malini, to establish the first programe in India for children with neurological disabilities. Motivating, educating, inspiring, challenging, coaxing—even coercing --family, close friends, government officials, corporate executives and doctors among others, Mrs. Alur succeeded in establishing the first organization in Bombay called The Spastics Society of India (now called ADAPT: Able Disabled All People Together).

But that was not enough...

Aware of the number of children and families still untouched by the minimal support they so needed, Dr. Alur focused on expanding services outside Bombay. Her constant challenging question to like-minded family members and friends, '*no services in the capital!?*', resulted in the first special school opening in 1978. The Delhi branch was called The Spastics Society of Northern India (now AADI: Action for Ability Development and Inclusion). The organization was spearheaded by Dr. Alur's sister Mita (Mrs. Mita Nundy) and her close friend Minu (Divya Jalan) both of whom already had a keen interest in and some experience of working with children with disadvantages and disabilities. Anita



Shourie, joined soon after, bringing in her invaluable experience as the mother of Adit.

Mita was an extremely inspiring leader. Dr. Mathew Varghese, Former Director, St. Stephen's Hospital, remembers –

“I forget the day and the year but around 1989 or 1990 as a young orthopedic surgeon I was invited to a meeting at AADI, then Spastics Society. There were children, parents, counsellors, therapists and other board members of Spastics society. I was late and slipped in to the meeting quietly. The meeting was in the open air of Spastics society building enclosure. I was preparing to listen to some boring speeches and perhaps some life story of rehabilitation of a child with cerebral palsy. Then someone, introduced Mitadi and she started speaking. The next 15 minutes or so I sat spellbound. She was so erudite, so clear in concepts and the way she put across issues were so electrifying that I was literally tingling with this exposure to a new perspective on children with cerebral palsy. I had a lump in my throat. She had moved me beyond measure. I was too timid then to go up to her and compliment her on her speech. That speech by Mita remains, till today, one of the most moving speeches I have ever heard. I hardly ever interacted with her except later in some of the board meetings at SSNI/AADI. She had changed my approach to children with cerebral palsy forever. To see them as human beings beyond the clinical cases to be treated medically or surgically.”



Mita's compassion and constant concern for those further disadvantaged by conditions like urban poverty and rural living resulted in the initiation of the Rural

project in Dayalpur. Soon after the urban services were started. The rural expansion compelled SSNI/AADI to include children with all disabilities, leading it to innovate suitable strategies to work with a more diverse group. Mita and other founder members always responded to new situations as and when they occurred. It was during the late 80s, when SSNI/AADI used this rural experience to re think and bring greater relevance to its programs via the model of community based services. It was this experience of working with all disabilities that helped SSNI/AADI to have a cross disability focus in its services as well as contributing in fora like the Planning Commission, UN Committees and other Government committees on policy & legislation.



Mita's sensitivity along with her extremely sharp and analytical thinking ability resulted in many innovative programs in SSNI/AADI. She took bold but much needed difficult decisions. Moved by the desperation of waitlisted parents and realizing that India did not have the capacity to start special schools in the numbers that were needed; she started a family training program. At a time when large numbers of trained physiotherapists and occupational therapists in India were going away to the Middle East and other countries creating a vacuum, she proposed a one year post graduate training program - Basic Developmental Therapy, as part of the School of Rehabilitation Sciences. Liz Carrington, a pediatric physiotherapist from London and Vandana Bedi, then Occupational therapist, developed and implemented the first course making Mita's initial idea a reality. Once convinced, Mita persuaded the academic as well as the Government

authorities to see the relevance of these programs. This is what ignited the creative expansion of services for people with disabilities.



The partnership between the three leaders in the early years, Mita, Minu and Anita , laid the foundation for the development of an organization with strong value based philosophy and a professional approach to the work in the area of disability. Gloria Burrett and Vandana Bedi succeeded them as Directors, consolidating the philosophy and expanding the horizons. Syamala Gidugu, who joined SSNI/AADI as a teacher in 1987, and now is the Executive Director, combines the legacy and the culture of SSNI/AADI with contemporary challenges and needs.

Mita was dynamic. Romi Khosla, the architect, who designed the building of SSNI/AADI said, “Mita knew no boundaries.” In her mind, anything was possible. Commenting on her spirit and will power in overcoming a medical prediction of limited life, Dr. Srinath Reddy, then a cardiologist at AIIMS describes “her unbending spirit (which) refused to accept the limits that medical science arrogantly sought to set on her life.” He further added “(I) thank her for giving me the most valuable lesson as a doctor. Not to take anything for granted.” Mita continued to guide the work of SSNI/AADI all through the 90’s, often having

meetings in her hospital room or suddenly appearing in a wheelchair straight from hospital to support the staff when the annual inspection was going on.



Mita spent long hours at work along with her team. This resulted in rapid expansion in the early years. Mita had no time for herself. Vinita Rawat, a much loved and feared senior teacher remembers... “The school was in its infancy. Mita had funds to raise to pay the salaries and the monthly rent, organize training programs, and meet government officials for further 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’ll 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.”



Mita often spent time counseling staff members, family members as well as children with disabilities when they were troubled. After a session with her everyone went away feeling good, nurtured and with a sense of direction for the future. Amrit Hallan talks about a learning through his student days which has stayed with him for life – ‘one has to learn to take responsibility for one’s actions’.

Mita was deeply spiritual. Gloria Burrett, the then Director of Services, talked about how spirituality came into the work of SSNI/AADI. She said” it is deep spirituality which helps us to sort out conflicts, forgive one another and feel empowered to work. This reliance on spiritual concepts is much more effective than any form of counseling. This concept of oneness has helped us cut across all barriers of religion, caste and social hierarchy”.

Mita never looked for personal recognition. This developed a culture in SSNI/AADI for collective ownership of work.



SSNI/AADI strongly believes that it is what it is today, because of the collective effort of hundreds of people – people with disabilities who contributed through sharing of their experiences of discrimination and exclusion and focused the attention for relevant services. They became a crucial part of the training teams and over a period of time joined in the advocacy programs. Families of people with disabilities also guided the efforts on what needs to be done beyond the ‘technical’/‘specialist’ work. Professionals who gave up more lucrative jobs to work at SSNI/AADI, individuals and companies who believed in the work and supported financially, officers in the government who gave their personal time to understand this emerging area of work, Professionals from varied fields, lawyers, doctors, architects, business executives, teachers, artists, who gave generously of their time and expertise. And neighbors, students, extended family members took on individual responsibilities, that made it possible for the work to continue.

All of this required constant focusing, planning, motivating, guiding and training which was initially taken up by Mita herself.

Today SSNI/AADI stands on a strong footing, with the second generation leadership taking on with the support of some of the founder members.

Mita's missives: A few excerpts



A personal note to her friend/colleague revealing her vulnerability (1997)

writing — I just felt so
tired and often overwhelmed
without you specially and
without the necessary
oversaws. I couldn't
have carried on
without the lord's
rescue, understanding and acceptance.

*Mita's address to a large gathering at SSNI/AADI
during the visit of His Holiness Dalai Lama in 1995*

comes, to include We ~~for~~ considered
discussed and debated these issues in the
last few couple of years and felt that
we too needed to transform our courses —
but in the direction of a ~~more~~ ^{greater} focus on
the social model of disability responding
to the ~~of~~ voices of disabled persons all
over the world and a few ⁱⁿ India, ^{yes} the
challenge today is to ~~gain~~ achieve high
technical standards in education, therapy,
counseling, communication ~~and~~ teaching ^{and their families}
equally to ~~help~~ help disabled persons ^{make}

informed choices about their goals in
Each of these areas. To teach
rehabilitation not as a ^{priority} esoteric, specialist
highly technical subject but within a comprehensive
social framework. To find ways of
deeply sensitizing our students ourselves
about human equality issues in a
country where hierarchy is so deeply embedded
class and caste structure and our very psyche

Excerpts from Mita's letter to her colleagues introducing a spiritual practice she knew that would add quality to the lives of people with disabilities

We live in bad times where there is a large slaughter of human beings and hatred is fanned in the name of religion, communalism and many other fanatic ideologies. SSNI is working increasingly with other organisations - our motto is to "unite with differences", with tolerance. Disabled persons, their families and volunteers come to more than 6000 families. There is a great need today for creatures of this earth to live together united in mutual concern and harmony. There are laws and logic discovered, enunciated by the scientists of the spirit that we need to understand and share with students in our care. All are encouraged to attend. There is a limited number who can be trained. All those who would like to avail of this opportunity are invited to give their names as soon as possible to Vinitha Nayer or Vidya, so that you can plan for absence from work during the timings mentioned in the attached schedule.

A paradigm of thinking, knowing, believing: Mita's legacy for SSNI/AADI



To work alongside Mita was to be immersed in a process that constantly challenged set ways of thinking, questioned a mere aping of the best of the west, and focused on the real stakeholder at the heart of all our efforts; the person with disability and the care giver. So often just by being a part of the reflective process of a case conference or the planning retreats initiated and chaired by Mita, we began to believe that complacency is a sin, that we are accountable to the people we work with, that professions need to cut across boundaries to deliver effectively in the spirit of transdisciplines and that the- centre- of excellence approach has to co-exist paradoxically with the responsibility to ensure the widest reach of services. The greatest impact on those of us who worked alongside Mita however will always be from her set of core values of justice and inclusion that stood starkly in the prevailing context of charity and welfarism in the 1980s. Values that are central to contemporary thinking and which we are still trying to do full justice to for them to really define our organisational culture. How grateful we are to have had a prophet, visionary and teacher in our midst!

Within us even today Mita's guiding voice provokes us to ask these questions of ourselves:

What does India really need?

At a juncture when SSNI/AADI was addressing the dearth of rehabilitation professionals by exploring its own training involvement, Mita's vision challenged the existing medical- model oriented physio/occupational therapy training courses in favour of more holistic person-centered and community-oriented courses. This was too radical to be easily accepted by others and yet today forms the basis of our knowledge of relevant content in ongoing courses. At a time when SSNI/AADI is changing its focus in the area of training, it is this core question that remains a beacon. Yet another example of the macro relevance underpinning her thinking was the concept of partnerships with community based organizations like DEEPALYA and LOK JUMBISH which heralded a new way of working – a building of the capacities of existing professionals to address the needs of people with disabilities within the communities that they were working in. The result was a wider impact with minimum resources and ensured inclusion for people with disabilities. Today, this conceptual thinking is translated as a “convergence” of “disability issues” into ongoing development programs.

Is this strategy really relevant in this context?

When CBR for example was making its presence felt in India, Mita was no easy convert. ! This stringent question was applied in full force compelling us to read, and to research for ourselves before buying into the concept. This was vintage Mita. We grumbled and how....but this was the way we learned. A vivid image of Mita is of her in a home in rural Dayalpur, with Dr. Anandlakshmi of Lady Irwin College, using sticks and mud instead of pencils and crayons, to make cognitive testing more culturally relevant to and cognizant of the strengths of rural children. To see through her eyes was to realise that rural children from preschool age could recognise their own fields as different to a neighbours rather than stay stuck with a blinkered view of narrow norms which devalued their potential.

Will the poorest gain?

“Keep an eye on the person who might not easily access your service”. It was this question, often asked, that kick-started the urban CBR programme at SSNI/AADI. It was a question that flowed from the deepest part of Mita. “The poor. Think about the poor! “Years later when she was no longer at the helm of SSNI/AADI, her informal sessions with people with leprosy, often on the street, with bhajans blaring from a tape recorder were high points for her. This was no duty, it was her nourishment. Mita's phone calls waking our consciences are legendary and were

often met with a moan, “Can’t Mita chill? It’s Sunday!” Apparently never, as long as human need was in existence. Her heart pain was never allowed to get in the way! “Let’s organise blankets for them. It’s so cold” or “Shuro says malaria is a real killer disease. We can prevent this. Can you get 300 mosquito nets and distribute them to the poorest in the slums. I’ll send Ramu with the money!” These are words that have the power to rock our consciences even today. This sense of the other, seemed to emerge from a well spring that flowed till the end.

Where is this service really needed?

Going beyond the limits of urban-based comfort and complacency, we were compelled to proactively encourage persons from all over India to attend the training courses and return to their far flung areas to initiate services. Stressed mothers supporting each other in Ludhiana, that young adult zooming into a prevocational set-up on his wheelchair and a child with cerebral palsy entering school in Shillong, or parents of children with cerebral palsy forming an association in New Delhi to address the burning question “Who will take care of my children, when I am no more ? “, or trained volunteers and teachers in Gwalior or trainees encouraged to set up independent NGOs for the most marginalised groups in urban poverty areas, are a few degrees of separation from this aspect of Mita’s vision.

Are we listening to the person with disability/ care giver?

What comes to mind is that of a frustrated mother who complained about her child not getting regular services at SSNI/AADI. No amount of explanations or alternative support was enough. We were a weary, angry, frustrated bunch of young staff who expected Mita to support us in this stand-off. What happened was so different as our attention was focused on the need of the mother underlying her ranting and raving. WE were the ones left doing a re-think of our emotions! We had to, and gosh how we were reminded to “sit on our egos that needed this appreciation for all our hard work. “

Does this programme include elements that nourish the soul, for those many bleak moments of reality?

Using India’s theism as a valuable resource and her own spiritual practice and conviction in the power of a connect with an internal force , Mita initiated individual and group sessions with a spiritual element that held many caregivers through their stress , anxiety ,depression and physical exhaustion and provided persons with disabilities with a sense of meaning and sustaining spiritual strategies through their ongoing struggle. None of us at SSNI/AADI can

forget the day a spate of harmless questions in Mita's soft voice were asked of us, "we focus on a child's body, mind, feelings...what about their spirits, their souls? If they were your children wouldn't you give them a sense of their inner strength, a faith in a power they could tap into? "Let's see what keeps us going when the going gets tough.... Shouldn't we share this with our students? "Mindfulness, strength-imparting mantras and spiritual discourses were regular inputs. With hindsight, this was a remarkable addition to the work, a transpersonal element, that contemporary research affirms is essential for wellbeing.

What will enable a thriving spirit that bonds people and creates a community ?

It is this focus that has kept alive within SSNI/AADI the spirit of sharing, enthusiasm, joy, mutual challenge, and bonds well beyond professional ties. How else can , there be unison despite differences, and that walking of the extra mile for each other? SSNI/AADI's family-spirit legacy is the outcome where celebrating with families and sharing each others joys and pains, create a connect that goes deeper and larger than simply sharing a work vision.

How do we ensure continuity through a next generation of workers ?

Looking way beyond the contribution of her generation and the next, Mita created an innovative supervisor's course and foresaw the value of a training component in a funding programme to complement the hands-on experiences of ADDIs workers. At least 11 staff including special educators, persons with disability, supervisors and trainers, a carpenter, basic developmental therapists and a counselor brought back to SSNI/AADI relevant information and experiences from CBR projects, Vocational institutes, Inclusive set-ups and academic Institutes from in China, Japan, USA, Africa and the UK. This was another way-before-its time Mita- inspired plan. It is a question we need to keep asking today to ensure a continued life of the organization and its ever widening impact. It is one way we can share and –sustain Mita's dream of justice, inclusion and compassion for all.

Mita...our last words are to you; our mentor, mother-of sorts, dear friend, alchemist and rare soul. You have left a legacy...one that goes way beyond that which is seen, one that is interwoven deeply in the depth of **our** thinking, knowing, and believing. This keeps you ever alive.

A Woman of Silk and Steel

Dr. K. Srinath Reddy

If I have to search for a reason to feel proud of belonging to humanity, in an era which Pope Francis aptly describes as one where the world is witnessing the 'globalization of indifference', I only need to recall the life of Sushmita Nundy (Mitadi).

I first met Mitadi as a patient in the All India Institute of Medical Sciences (AIIMS) even though I knew of her earlier as the wife of Samiran Nundy, a renowned surgeon at that premier institute, and also as the Founder and Head of the Spastic Society of Northern India. Apart from working as a cardiologist at AIIMS, I was also the Associate Editor of the National Medical Journal of India, of which Samiran was the founder Editor. I came to know him well professionally but had not yet met his wife in person.

It was in late 1988 that I first met Mrs Nundy. I had just returned from 16 months of stay in Canada after completing an MSc in Epidemiology at McMaster University, having gone there on study leave from AIIMS. I learned then that Mrs Nundy had been admitted to the Cardiology service of AIIMS a year earlier with chest pain. After investigations, she was diagnosed to have Syndrome X (angina with normal coronary arteries), a diagnosis with which doctors in London agreed. Her heart function was reportedly normal.

So it was a shock when she was brought to the hospital emergency, in late 1988, with severe congestive heart failure. This condition results from extensive damage to the heart muscle, often due to a severe heart attack and less commonly from other heart muscle diseases classed together as cardiomyopathies. On investigation, Mrs Nundy's heart problem was now diagnosed as cardiac amyloidosis, a type of cardiomyopathy. This condition is caused when the body produces an abnormal protein (amyloid) which gets deposited in the heart muscle. The heart becomes stiff, with restricted filling of blood and loss of efficiency in pumping it. As a result, there is fluid 'congestion' in the lungs, liver, legs and other parts of the body.

Clearly, the disease had begun insidiously a year earlier and had progressed to the advanced stage of cardiac failure. The diagnosis was confirmed by cardiac biopsy. Samiran's extensive professional contacts in US and UK were used to confirm the pathological diagnosis.

This was gloomy news for Samiran and all doctors associated with Mrs. Nundy's care. Chemotherapy, the only treatment for reducing amyloid production, is not effective in reversing the course of the disease. Supportive care, for treating congestive heart failure, was needed to reduce symptoms of discomfort but would not alter the dismal course of the disease. At least, that was the conventional wisdom of the time.

Samiran reviewed all available research evidence and consulted doctors at the Mayo Clinic who had the largest accumulated case series of cardiac amyloidosis. The average survival after the onset of congestive heart failure, even on the best available treatment, was six months and the longest recorded survival was thirteen months. It was at this time that I became the treating doctor for Mrs. Nundy.

She was a revelation. Samiran had already disclosed to his wife all the facts about her medical condition. He was known to be always forthright in everything he did. In this case, his respect for his wife did not allow him to hide the truth even if it was so unpleasant. He also wanted to discuss the plans for their young children with her, to learn about the mother's aspirations for their future.

She told me about this conversation. I expected her to be depressed and despondent. To my great surprise, she radiated calm confidence. "I am not going to die so soon" she said, "I will live to see my children grow up. I also have to continue my work with the spastic children who need care for their disability. I still have many things to do and I will surely live to do them." It was not bravado or denial which sometimes patients display when confronted with an unpalatable truth. It was born from innate conviction that she could battle the disease with her will power and not let it defeat her purpose in life.

My respect for her increased each time I met her. She wanted me to give her the unalloyed truth about her clinical status and test results but in return infused confidence in me that she would beat the odds. It was always an engaging conversation about many things in life, with the unwavering thread being her unbounded optimism. I came to know of her love for classical western music as well as her faith in Satya Sai Baba. By this time she had become 'Mitadi' to me.

In between periods of hospitalisation, she continued to work, going to the Spastic Society- sometimes in a wheel chair. She tended to her own children with loving care. She lifted Samiran's spirits with her cheerful confidence. My wife, who had started working with the Spastic Society as a developmental paediatrician, gave me accounts of Mitadi's devoted and inspirational leadership which continued to

guide the institution despite a disease that would have seriously disabled another person with a weaker will. Mitadi always greeted me with a warm smile and I invariably left her room a happier person than I was when I entered it.

Towards the end of the chemotherapy, she asked me if she could take Tibetan medicine as per the advice of His Holiness Dalai Lama's physicians who visited her. I told her that she could, provided she did not discontinue the allopathic treatment. She then started on the dual treatment which she continued since. Frankly, I do not know what worked but Mitadi did beat all the odds- and by a mile. She lived for 26 years after the diagnosis of cardiac amyloidosis. I say lived, not merely survived, because it was a full life.

After some years of a professional and personal association that I have cherished, Mitadi's care shifted to the Gangaram Hospital, which Samiran joined after an early retirement from AIIMS. I too left AIIMS in 2006 to lead a public health organisation but saw Mitadi on different occasions at different venues, lunching with her family or at a condolence meeting for a mutual friend or on a visit to her home. She was still vibrant, with a luminous smile that always lit up my heart. She gave up her leadership of the Spastic Society after suffering a stroke some years ago but continued to inspire her successors with her vision. Even her recovery from the stroke was remarkable and the way she overcame the challenges of the residual disability made me marvel at her will power.

Indeed, it is that indomitable will power that I credit for the medical miracle that was Mitadi's life in the last 26 years. She has not been recorded in the scientific literature as a case of astounding survival. Despite being the dispassionate scientist that he is, Samiran would not have attempted it. I would not only respect confidentiality during her life time but also would not know how to describe the vital ingredient of her therapy- her own unbending spirit that refused to accept the limits that medical science arrogantly sought to set on her life.

I write this now, a month after her passing, not only to pay a personal tribute to Mitadi's memory but also to thank her for giving me the most valuable lesson as a doctor. Not to take anything for granted. I am still a great believer in science but now I also recognize and respect the tremendous power of the human spirit that extends the power of healing beyond known medical treatments. I have also seen, in Mitadi's face, that the glow of goodness can dispel the gloom of illness. Her life provided proof that love for others can be a more powerful elixir than potent drugs. She will remain forever the inspirational memory of an exceptional human being- truly a woman of silk and steel.

अव्वल अल्लाह नूर उपाइया
कुदरत के सब बंदे ।
एक नूर ते सब जग उपजिया
कौन भले को मंदे ॥

**Awwal Allah Noor Upaya
Kudrat Ke Sabh Bandey
Ek Noor Te Sabh Jag Upjeya
Kaun Bhale Kau Mandey**



In Zen Buddhism ensō is a circle that is hand-drawn in one or two uninhibited brushstrokes to express a moment when the mind is free to let the body create.

The ensō symbolizes the beginning and the end; the wheel of life, death and rebirth. In the middle is emptiness, the goal of all meditation.

It stands for strength, elegance and absolute enlightenment and the illusion of duality.

For us, it is a symbol that holds the essence of Mita: her journey's purpose, her source and nourishment, her deep knowing and her message.