

1

OUR STORIES:

THE JOURNEY TO MEET AUTISM

"I am Sabari, your witness, your watchman, your biographer and your author.

I plan to write your story, for it is my journey too. I am your mirror of sun."

—Sabari, at age 18, letter to Lakshmi, December 2016

LAKSHMI'S STORY

As a young doctor I was employed in public and private hospitals in Chennai and Hyderabad, South India, while taking specialist training in pediatrics and neonatology (newborns). In the city's main intensive care unit, I was disturbed to see children and babies in the same room as adults without specially trained staff.

I held a vision for something better, and in a few years I set up the first private pediatric intensive care unit at CDR Hospital Hyderabad. I trained all the staff myself and we were given a separate unit for children and babies. Later I started my own private hospital called Little Hearts Children's Hospital. As a practicing neonatal intensive care doctor running my tertiary care unit, I was very busy. In addition to twenty beds of neonatal intensive care, there was an outpatient clinic. It was also my home, I lived and worked there.

Little Hearts became known in Hyderabad as a center of excellence for high risk pregnancies and newborn care. I was busy with following up high risk newborns for developmental challenges and working with a team of physiotherapists and trained nurses in developmental assessments and early intervention. We cared for children with cerebral palsy, downs syndrome, speech delay, and ADHD, as well as premature babies and deaf-mute children. I also visited the Spastics Society regularly. Little Hearts also became well known in the city for helping babies and toddlers with developmental delay.

I started seeing more families with children with attention deficit and hyperactivity syndromes. In my practice, I noticed that these children often had associated digestive weakness or intolerance to food or history of speeded-up milestones.

So working with diet protocols eliminating processed food, wheat, and milk became one of the first steps in approaching these children. I suggested a gluten free/casein free diet with the whole family following a new lifestyle wherever possible. I learnt that when the whole family changed their diet patterns and lifestyle with dinner and bedtime before 7 pm, the children showed consistent improvement in attention and behavioral patterns. Some severe ADD/ADHD children became completely better. Of course, some ADHD children did not respond to diet alone.

Around this time, I had my first encounter with autism. What struck me deeply out of this meeting was that I did not seem to exist for this child. There was no differentiation between me, the person, and my stethoscope, as he reached out and pulled the instrument from my neck. It was deeply disturbing for me to meet a child who was not aware of another human

being's presence in the room. The sense I had that he could perceive *objects* clearly, but did not seem to perceive *me*, stayed with me for a long time. I had more children like this visiting me in the clinic during the following months, and I started asking questions. I started a new file where I put these children who were difficult to help. Many other centers refused to see them. This journey, which started more than twenty-five years ago, has become my path.

My early years were focused on working with nutritional programs and exploration of all possible ways of cleaning the gut, including antifungal treatments and various supplementation products. Ayurvedic medicine has its origins in South India, and working with and researching in collaboration with traditional Ayurvedic practitioners gave me the possibility to move quickly into holistic, balanced, individually designed programs with the least amount of supplementation products or pharmaceutical, chemically produced medications.

Improvement in sleep and ease in managing children at home through everyday life around basic needs were my early observations with this step in improving gut function.

Simultaneously working with sensory integration programs and the immediate environment of the child at home and school was taken up, and this was the beginning of building therapeutic communities around each child.

Also at this time, I took my first steps into working with Carnatic music, which later became deeply integrated into the special school curriculum with two experienced music therapists employed on staff. I found the children could connect to rhythm and music as a bridge. Carnatic music is an indigenous traditional

music with a deep connection to the ancient devotional traditions of Hindu South India. It also has a medical aspect of music therapy as well as an orientation to the natural world—e.g. seasons and day/night cycles. Children who were otherwise unable to follow instructions could sit still and imitate the rhythm by tapping the right hand on the thigh. This is how Carnatic music is traditionally taught—through the rhythm (*Tala*) as primary. There are specific melodies (*Ragas*) directed toward gut cleansing and strengthening.

I also came across the work of Rudolf Steiner at this time—Waldorf education and anthroposophical medicine. Learning and diving simultaneously and deeply into anthroposophy and Ayurveda greatly helped me in this initial part of the journey of understanding children on the spectrum.

We had our first “summer camp” for this batch of kids in 2003–2004. It was a six-week program with a simple curriculum. My daughters were on summer holiday and needed something to do—they became wonderful helpers playing traditional games with these kids. These games involve challenging fine and gross motor skills, attention, and social interaction. The curriculum consisted of: nutrition; traditional Indian games; music.

Mainly I just watched—observing each child keenly. I saw that in these children the senses were not coming together to form a whole picture. This led me to read everything I could find on sensory integration. I travelled to Kerala to meet traditional doctors and learn from them. Ayurvedic texts speak of “eleven senses plus the one.” I was curious about this because Rudolf Steiner also speaks of twelve senses. I watched and concluded that each child had a unique set of sensory-motor processing problems.

After the summer camp, many children improved. The parents all said—“we want to stay!” I tried to give them home programs but they wouldn’t budge: they wanted a program outside their homes. We had to find a designated space out of which I could continue my work with these children on the spectrum outside my regular neonatal practice and commitments at the Little Hearts Children’s Hospital. That is when I started Saandeevani Centre for Healing and Curative Education in collaboration with my colleague Dr. Swapna Narendra. The founding staff members included physiotherapists Sridhar and Sushmitha Reddy.

The birth of Saandeevani

I chose the name Saandeevani out of my encounters and experiences working with these children. The name comes from Hindu mythology. I had these questions in the first few years of meeting children on the spectrum.

- Who is teaching whom?
- Are these children giving us an opportunity to respond to our inner calling?
- Are we educating them? If so, in what?

Around that same time, I heard a story from a friend of mine who is a great scholar in Vedic knowledge:

Saandeevani was a very, very old man who lived at the time when Krishna was born and raised on earth as the eighth incarnation of the god Vishnu. Krishna became famous for his qualities of compassion, tenderness, and love and is one of the most popular and widely revered among Indian divinities. Krishna is the bearer of all knowledge

and grew up to be the wondrous guide of the noble and striving bowman Arjuna in the Hindu epic the Mahabarata.

Saandeevani was a teacher. At the end of his life he taught the young boy Krishna.

In the story, the seven-year-old Krishna tells his mother, "There is a teacher for me, his name is Saandeevani, please take me to him." When they arrived, the old man rose up to greet him saying " Krishna, I have been waiting for you. If I can be your teacher this will be my final activity in this life. It is my destiny to be your teacher. This will release my spirit from the earth."

Traditionally, the teacher occupied a plinth and the student sat on the ground. But Saandeevani and Krishna both sat on the same platform. It is said that people who watched then wondered "who is teaching whom?"

Is Saandeevani teaching Krishna? Or is Krishna giving an opportunity for the teacher to fulfill his destiny?

Working with this first group of children with autism in South India, a few of us carried this same question: Are we teaching them? Or are we finding our destiny purpose in meeting them and serving their needs? That is how the name Saandeevani came to us.

Saandeevani located itself in a little house near the Little Hearts Hospital in the year 2004. On the staff, in addition to the medical team, were a dedicated cook and two untrained teachers who were drawn to the children.

Working with parents and families

“Since we cannot change reality, let us change the eyes which see reality.”

—Nikos Kazantzakis, *Report to Greco*

At Saandeevani, I worked with changes in lifestyle, deciding food programs, and changes in home environment to suit individual children’s sensory needs. This required spending many hours with parents and sometimes with grandparents. In some situations this also involved working with siblings. In most situations, the primary caregiver was the mother, but we also had fathers taking the role of active primary caregiver.

We offered parent workshops about diet and the healthy development of children and its close relation to sensory environment. During these sessions we also explored child development through the inner sensory experience of the child, especially around speech, hyperactivity, and the unusual behaviors we see in these children. We realized that many parents experienced a kind of self-healing by attending.

There were workshops where parents were taken through a journey of exploring the sense of touch and learning basic massage techniques. This empowered many parents in putting children to bed or handling meltdowns at home.

Handwork and craft groups with parents helped to carry certain therapeutic sensory activities into home life. Many families had outdoor and indoor play areas designed to support their child’s sensory needs. Swings and rocking chairs helped children with vestibular symptoms. The music therapists worked with individual parents giving very specific exercises to each child and teaching the parents.

Some parents could see the child in a new way by seeing them through my eyes. I would ask the parents to write a description of their child before the first interview. What the parent wrote about the child initially, and what I described after the first meeting was often very different. We spent time and tried to understand each other and what we were seeing. This helped in building a warm relationship between parent and child and also shifted how the parent experienced this child.

This reduced parental anxiety around behavioral issues and led to more openness and warm interest in working with the child at home. In some situations mothers found the serenity to continue with their life and career paths. Other parents found meaning in reaching out to other parents who are in need. We saw parents starting new initiatives to help more children, becoming special educators, training to become therapists, helpers, and assistants.

Siblings were always part of the picture at Saandeepani. Also, new babies came into these families making a big difference in family dynamics. For parents it was a positive, warm experience to witness what we call normal child development. It was reassuring, freeing from guilt, and also this helped in respecting the child with autism for his or her own way of living.

The relationship between the child on the spectrum and their sibling was special, and on many occasions we experienced big leap of positive development. Later, as the younger children grew up, what was fascinating was how they experienced and described their autistic siblings. There were situations where siblings needed special time and space where they could express their feelings. Once a year we celebrated “Siblings Day,” creating a special day for them. Where appropriate, we

involved brothers and sisters in practical educational and therapy activities.

The initial work at Saandeevani was guided by the warm collaboration between doctors, therapists, and parents. There was an atmosphere of exploration. Initially, we developed a parent education program, which evolved out of the requests of parents who wanted to learn more about child development, food, behavior and sensory processing in order to help their own children with autism. Some of the parents who took these courses began working at Saandeevani, some went on to study special education and became teachers. The case study here indicates a typical case in South India.

SAI KEERTHANA: THE GOD-GIVEN GIFT

Keerthana...our second child and the only daughter in our family, was born after a gap of eight years following the birth of our son Kalyan. Her mother was very confident that she was going to give birth to a female child. Keerthana's mother spent all the nine months of pregnancy reading holy books and listening to classical music. Hence, we dreamt that the child would definitely flourish in dance and music.

It was on March 12, 2000, at 8:44 pm, the happiest moment—when her mother gave birth to Keerthana. Keerthana was very fair with a birth weight of 3.5 kg. It was a normal delivery. After listening to the baby's cry, my wife asked the doctor "Is that a baby girl?" The doctor replied, "Yes, it is a very beautiful baby girl." We celebrated the day as never before. It was the first baby held and kissed by her brother Kalyan. The

very next day, I was promoted to Officer's cadre in my organization. Keerthana is a gift to us.

After her naming ceremony on the twenty-first day, I was transferred to New Delhi. Those were the days, we enjoyed every moment of Keerthana. Her first smile, rolling, crawling, her little words, sitting, first tooth, and her footsteps in the eleventh month and walking—we celebrated every moment. Kalyan enjoyed all his past thru Keerthana's moments. On her first birthday, she welcomed each and every guest. She danced to the music with other kids. She used to run from the kitchen to the TV room, when she heard the songs, ads, and title music of the daily serials. The timely vaccination was done for Keerthana. She used to imitate her mother in sweeping, mopping, and cleaning the household. She used to play with her peer group in the evenings. At twenty months of age, she started crying for a long time in frequent intervals. She stopped paying attention to us and also reduced eye contact. She loved to be alone. There was no improvement in her speech. She used to say only "Amma and Ammamma." She cried twelve to fifteen hours a day. She could not sleep in the night and used to sleep for just two to three hours in the early morning. She was restless throughout the day. It was a big confusion for us, what was happening to our loving child.

We immediately consulted an ENT specialist referred by Keerthana's doctor. The specialist did Audiometry for her and found no fault in her hearing. He advised us to join in play school for group interaction. He also expressed his doubt about the deterioration of speech—because of the language confusion between

Hindi and Telugu. We joined her in a play school, but it was of no use. Her crying increased and she started flapping her hands. This was the horrible time in our life that we were unable to understand Keerthana. She completed three years and there was no speech, poor eye contact, no socialization and imitation. Then we were referred to a developmental pediatrician— Dr. Praveen Suman. After observing her for ten minutes, she expressed her suspicion of *autism*. This was the first time we heard the word. Many tests were prescribed: CT Scan, EEG, Thyroid, etc. The reports were normal. Our doctor explained autism as a problem that affects communication and socialization. She suggested that we go see a behavior modification therapist. She did not co-operate and at the same time he was not able to manage her. We visited some institutions and therapists in Delhi. Nobody could give proper suggestions. Gradually, we came to know that autism is a disability which can not be cured so easily. At that time, I fell ill and was bed ridden for four months. Hence, her mother could not concentrate on her during this period. When Keerthana was four years old, we were transferred to Zaheerabad, which is 100 km from Hyderabad. We still visited the National Institute of Mental Health in Hyderabad twice a week for therapies. There also we could not get a proper response because of the frequent change of therapists. Nobody explained where and how to start the management of therapies for Keerthana.

Her brother Kalyan was also very worried about his sister. We prayed to God to show the proper way for her improvement (not only Hindu Gods but also other religions).

At last, I got transfer orders to Hyderabad. We met Dr. Usha Naik, Professor, Child Psychiatry, Niloufer Hospital. She advised to stop milk and wheat products immediately and also prescribed some protocols. We found Keerthana reduced her crying after the GF/CF (gluten free, casein free) diet was introduced, and there was some improvement in her sleep. Dr. Naik explained the sensory integration therapy. There we heard about Dr. Lakshmi Prasanna and her working with the senses.

We met Dr. Lakshmi Prasanna on April 5, 2007, and told the story of Keerthana. She is the only doctor who could spend more than two hours in a single appointment. She told us that Keerthana is still arriving from the spiritual world and we must try to understand her. She explained sensory integration and its importance for autistic children. She assured us of the improvement in Keerthana's behavior and also encouraged us with her valuable suggestions. She praised Dr. Usha Naik's service for autistic children.

Dr. Lakshmi suggested following diet and sleeping rhythms. She also suggested giving her ragi soup twice a day, which is a natural chelating agent. This brought a great change in Keerthana. She started sleeping for eight hours during night. This was a big relief for us.

Dr. Lakshmi suggested to us to apply for Keerthana to join in Saandeepani for the summer camp. Keerthana joined in Saandeepani as suggested and we observed the improvement in her. Her eye contact improved and her restlessness was reduced. During this time, we observed that Keerthana was able to express her

needs. She started indicating her hunger and toilet needs. We got the Saturday special classes report of Keerthana. We were surprised to know of her abilities and skills. We tested all the activities, which were practiced in school. She could do all of them.

Our confidence in Saandeevani became stronger and we decided to apply for her to join in regular classes. We requested Dr. Swapna for admission. Keerthana was admitted to regular classes on January 21, 2008, by the grace of Dr. Swapna and Dr. Lakshmi. We would like to express our gratitude toward Saandeevani. The staff of the school has lots of patience and love for the special needs children. Keerthana settled in school in a short span. In Saandeevani, children are not forced to do activities. They treat them like angels on earth. We observe one to one attention in Saandeevani. They concentrate more on touch related issues. Keerthana started eating by herself, wearing her shoes, and doing many routine activities independently. Dr. Lakshmi returned to India during the month of January 2008. She conducted many workshops for parents. This helped in the development of a positive attitude in us. Now, Keerthana is interacting with staff and other children in Saandeevani. She is performing very well with a little support. Saandeevani has given new life to us and to our daughter. Today we are in a position to accept the challenge and face it.

Long live Saandeevani!

AVVS Murthy (Keerthana's father)

Note: *Keerthana's mother became a trained teacher at Saandeevani and now helps educate other parents.*

In 2006, I was invited to work on a project researching Leprosy in Kathmandu. There I met Michael Kokinos, a physiotherapist from Australia. We were working together to help a quadriplegic child named Pabi, who was living in an orphanage for leprosy patients. This meeting had a dynamic impact on both of us that resonates in our working life to this day!

Our coming together changed the scope and range of my work with children on the spectrum and brought new color and tone to all that was happening through me alone up until that time.

Michael and I began to offer extensive training for special educators and therapists, mostly in Chennai. We also visited many other cities in India—sharing, researching, growing, and developing a working model.

We traveled together, staying with families, which often brought us into a working relationship with three generations of relatives. The key of our developing working model was working with and holding each individual child as a team:

- The physician working to heal the gut and supporting family dynamics.
- Therapists working with their hands out of a deep understanding of the twelve senses and also introducing craniosacral therapy.

Michael also brought his gift of rhythm and movement into our work—guided by his Greek ancestors! We offered many forms of training programs for teachers, therapists, and parents, covering subjects like child development, sensory-motor coordination, working with the twelve senses and sensory integration, and structured rhythmic movement. We did these in parent's homes, medical centers, and schools.

What was unique in this last ten years journey was building therapeutic healing communities and weaving them together. Our rhythmic, periodic travels between all these groups across the country wove a fabric, binding all of them together, and yet leaving them free in work, in their individual organizations. *Individualization with inter-connectedness*—this is, for me, one of the key therapeutic guidelines for autism.

MICHAEL'S STORY: MY PREPARATION AS A THERAPIST TO MEET AUTISM

Raised in a Greek family in Melbourne, Australia, I chose to study physiotherapy. During the training, I became aware that I was filled with questions that my lecturers could not answer. I studied both at the Melbourne University School of Medicine and the Lincoln Institute School of Physiotherapy. While I loved to study anatomy, kinesiology and physiology, I was attracted to the mysteries of the interweaving of body and psyche. But the course content was nailed down to materialistic, biomedical science.

For six hours each week, in a large hall filled with tables upon which human cadavers—preserved with formaldehyde—were resting beneath white sheets, we practiced dissection. In the first year I dissected all the muscles and nerves of the limbs. One day, I found on the table next to our cadaver a range of electric tools. We were instructed to draw a circular line around the forehead and remove the skull with the saws, drills, hammer, and chisel. Glancing around at six students to a table sawing and hammering away it was like watching some kind of horror film and many students fainted

that day. After an hour of painstaking work with the hardware tools—I was working with the hammer and chisel to remove the top of the skull—suddenly, with a splash of fluids, it was done... I then held a human brain gently in my cupped hands—what a moment for a nineteen-year-old!—the wonder of its beautiful form, symmetry, and a blunt knowing that what I was holding was now *lifeless*. Precisely at that moment, my questions came again—from where is the animating principle? What moves this flesh from inertia into life, creating movement, laughter, a human personality? Is each of us just the product of chemistry and electrical impulses in a brain? What is the difference between this brain I am holding and the one in my skull?

I entered the clinical field of neurology, and over the years became a hospital-based specialist in neurological rehabilitation. For many years, my daily work was helping patients who were paralyzed following a stroke, brain injury, or multiple sclerosis. It was clear that brain science was a field full of theories and possibilities but no real scientific consensus. Looking back, it's clear to me that some of the experiences I had at this period of my life prepared me, in different ways, to meet the bigger enigma presented by autism. Here are the stories of those experiences.

Coma care: Gary's emergence

Gary was a thirty-year-old father of two who had suffered a severe head injury in a car accident and, as a result, was in a deep coma. There were a number of unfortunate patients in a similar condition and the physiotherapy department would allocate a team to do passive movements daily in order to keep the muscles

and ligaments moving and flexible and prevent them from stiffness and spasticity. At the age of twenty-five, I was allocated to that team with a few colleagues.

Using the “tilt table” involved two of us lifting the dead weight of Gary’s body onto a padded table with a large footplate. Thick straps held his ankles, knees, hips, and chest in place, then the electric table would tilt from horizontal to upright, approximating a “standing position” in space. This provided some weight-bearing through the legs, keeping the bone minerals strong, while also allowing us to stretch and move the fingers, hands, and arms.

Imagine this scene: four or five coma patients on the tilt tables, with the therapists passively moving their limbs. This session would take place at 9:00 am each morning. The patients were completely unresponsive, unmoving, with glazed eyes, a blank facial expression, usually dribbling from the mouth. Some of these brain injured people stayed in a coma for months, even years. Many died from complications somewhere along the way.

Have you ever seen a human being in a coma? It is such a mystery—one sees the human flesh, alive with beating heart, pulsating fluids and breath, but where is the awareness?, Here is the body, but where is the consciousness? What has happened to the person? Where did they go? Do they still have sensations? Do they see or hear?

This was like the next step from being with the cadavers—the dead person has flesh and no life or awareness; the man in a coma has life—living flesh. But where is the awareness, the personality? Regarding coma, the general medical consensus is no—they are brain damaged and so they do not see, hear, feel.

There were always a number of hospital staff who handled these human bodies with irreverence. Like they were in a warehouse moving boxes. I remained optimistic and would always search and scan for the slightest response, the flicker of an eye or the fingers, the slightest awareness even if there was none. I lived in hope, a hope without any evidence or precedent. I would come to work, warmly greet and talk to Gary as I stretched his arms and fingers on the tilt table. I would explain what I was doing and then just talk about the weather, football, anything, for weeks and weeks.

A new “physio” came to join our team and brought in a radio with big speakers—he liked to listen to “Funky Wednesday,” a soul music program on the radio from 9:00 am to 10:00 am. We liked Ben and his music, and soon Wednesdays became our favorite day—the young physios would sing along and, like an aerobics class, we moved the arms and fingers to the rhythm of the music!

One Wednesday morning two of the physios got carried away along with James Brown on the radio and began a comical dance, complete with pointing fingers and kicking legs. In the flailing of hair and limbs the female dancer accidentally kicked Ben square between the legs and he went down, clutching and moaning (and also exaggerating like a comedian). It was hysterical and the rest of the team laughed and laughed. As our laughter subsided I heard a deep, slow and moaning laughter continue. Turning around we all watched as Gary, upright on his tilt table, laughed and heaved and dribbled and even raised one of his arms! His eyes were sparkling. It was a miracle—Gary had emerged from coma. And it happened on funky Wednesday. Over the next months, with daily physio and therapies he went on to learn to walk, eat, and speak, and he returned

home to his family—with some disability but certainly not in a coma.

After he learned to speak, Gary recalled to me, word for word, some of the things I had told him while he was in a coma. He would often hug me and cry saying, “It was you! Thank you, thank you for talking to me every day, that is what kept me going, hanging on inside my body.”

So Gary taught me that it *is* possible to have *no output* in terms of the body—eye contact, speech, even movement but to be fully conscious and present inwardly.

I have never forgotten that.

The social consequences of an individual’s illness

John was another young man with a similar story—car accident, brain injury, coma.

I worked with his body daily. John’s sad trajectory was that he stayed in a coma for around a year and then he died. One does sit with questions of the meaning of an event like this—why didn’t he just die at the scene of the accident,? What could the purpose of that year in a coma be?

Those questions led to reviewing that year from a social perspective. He received many visitors and I got to know to them all. I recall one day a vocal argument broke out by the bedside. It was clear that family members and relations had been estranged for years. Initially there was intense conflict expressed between family in terms of his management and guardianship. Our social worker had to mediate many meetings. Over a year many of these relationships were healed as relatives met

and cried together while coming to visit John who lay there in a coma. Years later I wondered—could it be that individual illness has a broader social function and consequence? This question emerged out of pure observation in the scientific tradition of phenomenology. This is not the same as saying the accident was caused by social context, but simply that the phenomenon of illness can bring dramatic social change in the community. This raises deeper questions.

Work in Aboriginal Australia

Just prior to meeting autism in India, I had spent four years working on an Australian federal government project in remote schools in Aboriginal communities of the Northern Territory. I lived in the little town of Katherine and traveled out by small airplane and four-wheel drive vehicle to the traditional lands of these ancient tribal people. This project was aimed at inclusion of children with disabilities in a cross-cultural setting to help them with physical disability aids and school inclusion.

I dived deeply into this work and sought to bridge the cross-cultural barriers. I met an intriguing and mostly misunderstood culture and people. Over time, with much patience and restraint, I made some wonderful friends and learned that it is the tragedy of Australian history that this relationship with the first people was handled so badly. Generally the government medical personnel were frustrated by a seeming lack of interest of the Aboriginal people in health, and particularly rehabilitation of the disabled. What I found was something radically different—these families were already practicing a culturally appropriate and complete social

inclusion, with different priorities than we in Western societies.

Larissa was a young girl of nine years with cerebral palsy living in a small Aboriginal community over 100 km from the nearest town. She could not walk, but rather crawled around, similar to what I had seen in remote areas of third world countries. The government allied health team gave her what every child with cerebral palsy gets—a wheelchair, plastic splints, and a regime of stretching exercises to be done by the family.

Talking to Larissa's parents and grandmothers over many months, it was clear they were not passionate, interested in, nor grateful for our laminated exercise programs and night splints. The team were confused, judgmental, and upset at this "lack of compliance."

Yet it was easy to see that they loved Larissa dearly, and that for them the priority was her social inclusion in the community. Larissa was very joyful, intelligent, and clearly loved by the other children for who she is. The elders and children would always include her in fishing, hunting, games and ceremony. They made a place for her and she was never left alone.

Stretching, strengthening, and "fixing" her physical body was not a concept familiar to them, it brought perplexed and inquisitive looks as the parents and elders tried to listen. The government team spoke of spasticity, tight muscles, and the need for plastic splints and stretches. The community answered that she got tight muscles when she was alone and stressed, so they made sure that everyone kept her happy and socially included—when she was happy, her body was soft, they told us. The idea of splints and stretches to achieve the same purpose that care of the soul could achieve was strange to those people.

As we shared perspectives I could see that, to them, Larissa was perfect as she was and did not need fixing. They saw her in soul and spirit, not as a disabled physical body. There was no fighting against what was there. The priority was her bright cheerful spirit and the inclusive relationships with community, not the limitations of her body. There was no anxiety in the parents about her economic future, her job prospects, her lack of independence and all the work that meant for the family.

The famous blind Aboriginal singer Geoffrey Gurrumul Yunupingu sings:

*I was born blind,
and I don't know why
God knows why,
because he loves me so
As I grew up, my spirit knew
then I learnt to read the world of destruction
I heard my mama, and my papa
crying their hearts in confusion
How can I walk
straight and tall in society?
please hold my hand*

Perhaps this simple expression of trust can speak to us. There is certainly an acknowledgement that independence is not the aim—but rather Gurrumul's request which points to relationship and community, namely—"please hold my hand."

Back with Larissa, our Individual Client Programs

aimed at independence began to seem to me to be laced with cultural imposition, the continuation of colonization. Did we have a right to force our goals on this child and family when they clearly didn't share them? Mostly my colleagues and government management simply did not enter discussion around these points. Again I carried these questions alone.

Leprosy project in Nepal

I first met Lakshmi in Kathmandu where she was a local physician for an international leprosy research project. The project was fascinating in that it had two aspects. One was to provide modern medical care in the usual sense, the other was to provide soul care for those affected. This soul care began with research into the inner experiences of those with leprosy. Often it was children who contracted the disease at the tender age of ten to fifteen years old. What followed was a period of social exclusion, and these children often wandered alone trying to survive in a world that rejected them. Lakshmi and I sat with people all over the Kathmandu valley and Pokhara, listening to the life stories of over 100 people. Together we synthesized what was common in their stories, their experiences with this illness, and we worked with a team to develop an approach of care of the body and soul.

This project was coordinated by Dr. Michaela Glöckler and the Medical Section of the School for Spiritual Science at the Goetheanum in Switzerland, and here I learned more about the approach of anthroposophic medicine.

Specific to leprosy is the loss of sensation and the experience of pain. The fingers and feet become

completely numb. The many problems that follow are a result of this loss of sensation. So to summarize the impact of this work very briefly, leprosy work brought home more strongly the importance of the sensory system in human life. I also recognized that Lakshmi was not like any other doctor I had ever met. I was amazed by the depth of her care, the strength of her will to heal, and the way she could connect to people. The Nepalese patients with leprosy opened up to us with warmth and love, they cooked meals for us and welcomed us into their homes, and this was a rich time for us both.

Meeting autism in India

Although I had done a lot of work in pediatric physiotherapy and early intervention with cerebral palsy and developmental delay, I did not work closely with autistic children until I met Lakshmi in 2006. In Australia, children with autism were seen by speech and occupational therapists (OTs) but not physiotherapists. Generally, these children were deemed not to have movement related problems, for they can walk, grasp objects, and move all their limbs to full range of movement. It is interesting how our medical system separates out and draws a line between movement and sensation as if they are separate and unrelated. OTs do “sensory integration” while physios work with movement disorders. One thing that struck me as I visited various autism centers was this idea of “sensory integration” and how it was being practiced; for me, it was happening at a very superficial level—but I sensed that this was an area calling for deeper inquiry.

In September 2006, I was resident physio at Saandeepani for six months. Over the next five years, I

would visit and work there three to four times each year. This was the research period. I worked closely with Lakshmi's team, including Dr. Swapna Narendra and the physiotherapist Sridhar Reddy.

What a challenge I met there—words cannot express it! Here were children in perpetual movement—there is no speech, no eye contact. They moved in such strange ways, each in a unique, individualized manner. Often the movements have no recognizable function in terms of earthly objects or needs. I would just sit and watch these kids moving, and I was utterly perplexed.

In my entire professional career I had never felt so useless. There are not many foreigners and tourists in Hyderabad. It was the talk of the local chai stands that this Aussie physio was working at Saandeepani. Parents came and brought their children to see me hoping for a miracle. They would look at me with desperation in their eyes. But I had no answers.

When I started meeting these children in Saandeepani it took me back to the same questions I had carried unanswered since my student days. What is the relationship between mind and body, psyche and soma, the brain and human capacities?

By 2006 I had already met the work of Rudolf Steiner—his concept of the twelve senses and the relationship of movement, sensation, and speech. Here was someone who was asking the questions that were carefully avoided during my medical training. I was curious.

Saandeepani

My room was small and had a custom-made treatment table, low and wide, in its center. The children

could be at times unpredictable and aggressive—many times I was scratched and squeezed, hit and bitten, yet I never perceived any malice in these actions. I found that framed pictures or objects would invariably get smashed, thrown out the window or bitten into. So the room became otherwise bare, apart from some soft beeswax for hand play. We painted the walls in gentle colors. It was a research space containing just four things: me, the child, the beeswax, and the padded table to lie on. Much beeswax was turned into chewing gum or thrown at the circling fans overhead!

Following my intuition, initially I would mirror the children's movements. I would watch and copy the particular quality of hand flapping, rocking, or other self-stimulating movement with the question: How does it feel to do this particular movement? What is the inner experience? Why would the child need to do this repetitively? I learned that these movements produced similar results; if you flap your hand strongly for twenty seconds, then stop, there is an aftereffect—I would describe it as a heightened experience of the location of your hand. The aftereffect lasts for quite some time. Is it possible that all these extra flapping, rocking movements are related to an attempt to feel ones own body? Much later I came across this writing from Tito Mukhopadhyay, a fourteen-year-old boy with severe autism. He says:

“I am calming myself. My senses are so disconnected, I lose my body. So I flap my hands. If I don't do this, I feel scattered and anxious...I hardly realized that I had a body...I needed constant movement, which made me get the feeling of my body.”

While doing this mirroring, I also found there were often moments of fleeting eye contact, and a sense of interest in my presence. Only later was I told that “mirroring” is a legitimate form of treatment in autism. Previous studies have suggested that being imitated by an adult is an effective intervention with children with autism to facilitate social responsiveness.

Gradually, the children learned what the large treatment table in the middle of the room was for. They began to hop up and lie or sit on the padded table to receive a treatment. One thing I knew for sure—I would not use force, coercion or any kind of fear, punishment, or reward. That meant waiting for the child and being led by the child.

My aim was to find with each child a contact or connection and work from there. I was also trained in craniosacral therapy. The American cranial osteopath Dr. John Upledger had published some promising results working with autism, and I was keen to see if this form of treatment could help. I developed the idea that each child has a “handle,” which could open a door to connection. In each, the handle was hidden and unique. Some required firm touch, while others needed ten minutes of freedom to move about and make sounds, unhindered, before they would hop up onto the table. I almost always worked without words, holding a clear intention but without speaking, and using only the medium of physical touch. My aim was that the child would lie on the table and let me examine the craniosacral rhythm in different parts of the body to see what I could find to treat.

Amazingly, after a few weeks of treatments, some of the children would burst through the door, come into my room unannounced, lie on the table making noises

and then grab my hands and place them on the areas they wanted—often on the forehead or neck, between the eyes or on the face—the children would use my hand to feel their own bodies. Sometimes softly, other times firmly. And they would calm down dramatically. Then without warning, simply hop up and walk out again back to class.

I was amazed that even at these times, there was still no eye contact. I trusted the children and tried to provide a space of unconditional acceptance. There was a clear sense of meeting the child's intention in the non-verbal space. I learned to allow the child to direct me during the session and expect nothing further in terms of “appropriate” communication.

Of course, this running in and out of class caused a great deal of chaos to the teaching staff down the hall. I recognized that this was leading to my next task: teaching and sharing this way of touching to promote body awareness with the teachers and care staff. Lakshmi and I did many workshops with parents and teachers on touch, massage, hand gesture games, and the twelve senses according to Steiner. Witnessing the effects of consciously directed touch was dramatic. I could sense that children were coming to me because I knew how to give them a safe and secure experience of their own body and that on their own they did not have the gift of this bodily experience that we take for granted. Sensory Integration became my area of specialty, and I used a combination of touch and massage and hand gesture games with sound and rhythmic movement.

On a technical note, I began working with craniosacral decompression techniques for the base of the skull: the ethmoid and sphenoid bones. This area was often so incredibly tense. I had sensed that the children were

holding the muscles of the face and head locked tight in an attempt to block out sensory input or light or sound. In the environment of the physio room, they could relax. Some children with challenging head hitting and face tapping behaviors improved. I went through a short period of feeling rather competent, important and special. But these behaviors would return with environmental stress or changes in sleep or diet. Sometimes I would return to Australia for a few months only to find on my return that the head banging was as severe as before. To make lasting change I had to address my egotism and we had to address the environment.

I began to take my place as a co-worker, without claiming any special status for my specific therapy, but rather placing it in service of the child and the whole community. I did more education for parents, teachers, and therapists about the role of touch and the senses. For me this was the beginning of curative education and the weaving work of social therapy; in this, Lakshmi was my guide—she was always finding ways to share knowledge and bring diverse groups into working together. Bear in mind that this is not easy in South India, where old class and caste systems tend to hold sway during social meetings. Lakshmi is not afraid to cross these boundaries to bring people together on behalf of each single child with autism.