

# Autism Spectrum Quarterly

## Sleep and Autism Avoiding the "Nightmare"

### You and Your Child's Behavior

### How to Avoid Compassion Fatigue and the "Parent Trap"

### A Sibling Searches for Answers

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# Spotlight Internationale

## BREAKING THE SILENCE

# THE LONG ROAD TO ADDRESSING AUTISM IN NEPAL

Part One of a Two-Part Article

Cynthia Ryan, Ph.D.

When Dina Bangdel, Ph.D., an associate professor at Virginia Commonwealth University specializing in South Asian/Indian art, returned to her native Nepal in 2003, her mother-in-law took Bangdel's son, Neal, to Surya Binayak Temple in Bhaktupar, a traditional city on the outskirts of Kathmandu. Not quite two, Neal had been diagnosed with speech delays earlier in the year, and his grandmother thought the trip might provide the help the boy needed. A temple devoted to the Hindu god Ganesh, Surya Binayak is known among locals as a place to bring children who are struggling with language issues, whether speech delays or deafness.

After visiting Ganesh's shrine, devotees climb further up the hill to the shrine of Parvati, Ganesh's mother. There, they place the child in the center of a small, empty space within the shrine and leave for a few minutes to allow the blessings of Parvati to be bestowed. According to legend, in the coming days, weeks, and months, the child will begin to utter his or her first words.

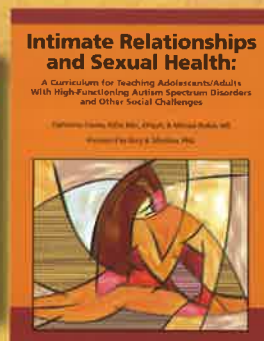
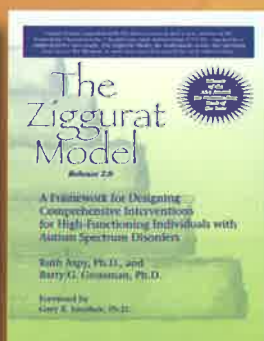
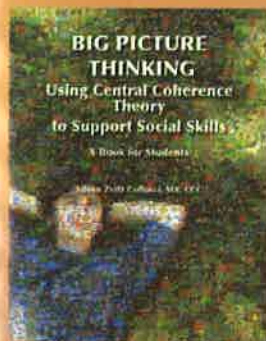
A year later, Bangdel and her son returned to Nepal, and to Surya Binayak, this time armed with a diagnosis of autism. Nearing three years of age, Neal displayed major speech and social skills deficits. Though the diagnosing physician in

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America had steered Bangdel toward recent studies, websites, and an array of potential specialists to help her son, she was compelled to seek assistance from a favored deity alongside conventional medical advice from the Western world.

For many permanent residents of the Kathmandu Valley, and in other regions of Nepal, autism remains an unidentified condition. The country lacks both the infrastructure to train physicians and caregivers in the complexities of autism spectrum disorders, and the social and political support to address the needs of those individuals who defy notions of normal behavior. As a result, families of children with autism are forming their own community in search of a common goal. With the assistance of experts from other countries, where advancements in autism research and care are more visible, the founders of Autism Care Nepal are working hard to improve the opportunities available to their children.

### Contextualizing Autism in Nepal

Nestled between India and China, Nepal is a country of approximately 29 million people. Almost one-quarter of the Nepalese population lives beneath the poverty level, and fewer than half of those 15 years and older are able to read and write. In fact, Nepal is one of the poorest and least developed countries in the world, with several factors, including its geographical location and history of political strife, contributing to its instability.

For Nepalese who demonstrate one or more of the characteristics of autism spectrum disorder (ASD), few options exist. During conversations with Dr. Sunita Maleku Amatya, an anesthesiologist, and Dr. Kapendra Shekhar Amatya, a surgical oncologist—parents of five-year-old Krit, diagnosed with autism at 26 months—I began to grasp the immense hurdles that parents of children with autism living in this part of the world must overcome.

Dr. Sunita, who serves as chairperson of the nonprofit Autism Care Nepal, tells me that in a culture ill-equipped to handle the number of cases of differently-abled children and adults (many of whom have intellectual disabilities), people exhibiting signs of autism receive little priority. The lack of education and awareness, even among medical professionals in Nepal, exacerbates the situation. “Children are sometimes not diagnosed at

all, or not until they are nine or ten years old,” says Dr. Sunita. And when they are, there are “no developmental psychologists or behavioral therapists” or any of the other specialists you might expect in other countries to turn to for guidance.

The social stigma associated with traits of autism spectrum disorders also prevents families from receiving the care they deserve. “A mother of a child with autism will be told, ‘you are the cause’ or ‘you are being punished for something in your past life,’” Bangdel notes. Oftentimes, “when something is wrong with the child, the husband leaves them both” to escape the bad karma that supposedly created the situation and the stigma that is now associated with the family.

School is rarely a suitable alternative either, since children are often denied access for disruptive behavior. Or, Dr. Sunita shares, “they are neglected by teachers and peers” who don’t know how to handle them. “Parents do not know what to do,” Dr. Kapendra adds, a point painfully illustrated by stories of children locked in closets so that their parents can leave the house to go to work, or of children shunned by grandparents, aunts or uncles, because they bring chaos to planned gatherings. “Imagine how hard it is to be rejected socially,” Bangdel says, “in a culture that values the family so highly.”

### Informing and Inspiring at Autism Care Nepal

On April 2, 2008, World Autism Day, Autism Care Nepal ([www.autismnepal.org](http://www.autismnepal.org)) was founded by Drs. Sunita and Kapendra, along with other families in the Kathmandu Valley, to provide a center for parents and children to come to, share their experiences, and learn from one another. The facility is staffed by parents, all of whom participate in hands-on workshops geared toward providing a better understanding of ASD and improved interactions at home.

Dr. Sunita also lists a number of services provided by Autism Care Nepal that were previously unavailable to anyone seeking assistance with a family member exhibiting the warning signs of autism: proper diagnosis, psychological and ADOS



A boy swings in the back play area at Autism Care Nepal.

—April Garcia

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assessment, parent counseling, mother-child programs, sensory integration therapy, music and art therapy, and a day care service run by parents—many of whom hold down full-time jobs.

Available services have depended upon partnerships with international organizations like the USA-based Knowledge for People, and on-site workshops and informational sessions run for Nepalese pediatricians, educators, and psychologists by experts from India. Many of these newly-trained professionals now offer their services on a rotating schedule to children and parents who utilize the center.

The past three years have also involved a concentrated communication plan for spreading the word about autism through local media and professional presentations at conferences in India and Nepal. Dr. Sunita has advocated tirelessly for resources and recognition of the special needs of people with autism in Nepal, speaking to politicians and seeking amendments to the newly-devised constitution.

But Autism Care Nepal is about more than formal training and staffing concerns. "We also come together for holidays and special celebrations like a child's birthday," Dr. Sunita says. "With these families, we are comfortable and know we are not judged," Dr. Kapendra adds.

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# AUTISM CARE NEPAL PHOTO ALBUM



A grandmother with her 18-month-old, nonverbal grandson whom she was taking to Parvati's Shrine for a blessing



Ganesh Shrine at Surya Binayak



Sunita, discussing Autism Care Nepal and interacting with parents undergoing training

Right: Parvati's Shrine where parents or other family members leave their children for blessings



Right bottom: Krit, with his parents Sunita and Kapendra



Krit: running alone down the slide



—Photos by April Garcia

## Breaking the Silence

As I watched the children enjoying a snack before leaping onto swings at Autism Care Nepal on the day I visited, I marveled at how much had been accomplished here in just three years. But then, the parents who maintain this haven are passionate and committed to a brighter future for their children, one in which their hopes and dreams will not be silenced.

Slowly, their voices are being heard. 🇳🇵

Part Two of "Breaking the Silence: The Long Road to Addressing Autism in Nepal" will focus on the experiences of one mother of a child with autism in Kathmandu to illustrate how cultural norms contribute to the social stigma of autism and restrictions on care. Information will also be provided for assisting families at Autism Care Nepal who are struggling to change the face of ASD halfway around the world.

## BIO

Cynthia Ryan, Ph.D. is an associate professor of English at the University of Alabama at Birmingham specializing in rhetoric and writing. Her work has been published in professional journals including the *Journal of Medical Humanities*, *Journal of Business and Technical Communication*, and *JAMA*. She is also a freelance writer with clips from national magazines and newspapers including *CR Magazine* (newly named *Cancer Today*), *MAMM*, *Chicago Tribune*, and *USA Today*. Recipient of a 2011 Clarion Award for her article, "Homeless With Cancer," Ryan blogs at <http://cancerhitsthestreets.wordpress.com/> and may be reached at [cynryan@uab.edu](mailto:cynryan@uab.edu).

