

India

Heard Around the World

A VISION FOR INDIA

BY R. G. DESAI, M.D., PH.D., WITH ANJALI DESAI

In 1964, my wife gave birth to our daughter Anjali. About one month later, Anjali was diagnosed as being profoundly deaf. That year, 60–70,000 children were born deaf due to a rubella (German measles) epidemic in the United States. Early in my wife's pregnancy, she had been infected with rubella by a neighbor's child.

We wanted the best chance for Anjali's development. When she was three years old, we enrolled her in the John Tracy Clinic in Los Angeles, despite the 45-mile drive to and from our new home in Newport Beach, Calif. After several months of the Clinic's oral-only approach (i.e., lip-reading and speaking only, no signing), we were frustrated with Anjali's slow progress. Along with several other parents of deaf children, we researched other methods of teaching. We found and invited Dr. Roy Holcomb to start a "total communication" school locally. Dr. and Mrs. Holcomb from Gallaudet University were both deaf. They espoused a total communication approach that used sign language as well as lip-reading and speaking to teach children with hearing loss to

communicate. A new school was started in Santa Ana, Calif., with the support of the local superintendent and legislation guaranteeing children with hearing loss equal access to education.

While Anjali attended school, we did too. The school's educational philosophy put great emphasis on parental and family support for the child's success, so my wife and I and all our family attended evening classes in sign language. We also always tried to provide emotional support to Anjali as she overcame the frustrations common to children with hearing loss.

After finishing high school, Anjali earned both a bachelor's and master's degree from Gallaudet University and now is a career coordinator at Gallaudet. She met her husband at Gallaudet and now has two hearing children and leads a successful life with deafness. Early detection and intervention made the difference in her success.

In contrast, I consider the lives of the many children in the developing world that do not have the advantages of immunization, early detection and early intervention.

With widespread inoculation for mumps, measles and rubella

(MMR) today in the U.S., there are hardly any cases of deafness related to rubella. However, in my home country of India, this is not so. With its more than 1 billion inhabitants, India also has one of the highest rates of deafness in the world! The exact number is unknown but is estimated at over 55 million and many cases are related to the completely preventable rubella.

Currently in the U.S. and some European countries, children are screened at birth before leaving the hospital. Then appropriate intervention (hearing aids, surgery, etc.) can be implemented. In India, deafness is usually detected when a child is between four and six; by this time most of the ability to acquire language and communication skills has been lost. Regrettably, the child is called "deaf and dumb." Lack of parental education and the belief that deafness is God's punishment leads some parents to admit their children to an orphanage.

Early detection and intervention exists only in a few very large cities. Additionally, economic conditions and lack of education are major obstacles to the use of hearing aids



Photo by Lakshmi Prabhala

R. G. Desai, M.D., Ph.D., (left) with the president of India, Abdul Kalam.

Photo courtesy of R. G. Desai



and other amplification devices or modern communication devices like TTYs and accommodations such as closed captioning of television programming. Overall, the education for children with hearing loss in India is primitive and only in the large cities are there schools equipped to provide adequate accommodations. Even now, the use of sign language and total communication is not widespread and sign languages differ from region to region.

There exists only a fragmented vocational education system for people with hearing loss in the larger cities of India and none in the rural areas. People with hearing loss often are unable to realize their potential and add a burden to their families and the nation. Despite laws against discrimination, the average person with severe or profound hearing loss faces a life of hardship with menial labor or begging on the streets as their only “vocational” option.

The contrast between my daughter’s success and the conditions of most people with hearing loss in India has long troubled me. Over the years I have made various trips to India to do what little I can to assist on the front lines of this battleground. Continued frustration about systemic issues motivated me to meet with the President of India, Abdul Kalam, and others to talk about deafness in January 2007. President Kalam is an internationally known defense scientist and has an interest in the cochlear implant.

He is currently researching how he can make hearing assistive devices economical for the people of India. As the author of *India – A Vision for the New Millennium*, Kalam supports progress in hearing health for his country.

I met with the president at *Rashtrapati Bhavan*, the Indian “White House,” in his luxurious office, a 1,000-square-foot room that overlooks a small pond with water lilies, peacocks and other birds.

Flanked by two secretaries transcribing our conversation in shorthand, I discussed two goals that would impact the high rate of deafness and the people affected by it: 1) Vaccination for the whole of India with MMR vaccine to prevent many birth defects – deafness and blindness among them; and 2) Early hearing loss detection and intervention on a national basis. The productive meeting left me hopeful that the president will move forward with his plans for “a vision for the new millennium.”

Also on this trip, Dr. Chandrasekhar of Patna Medical

College and I lectured at Apollo Hospital in New Delhi to medical students and physicians. And I was honored to be the keynote speaker at three annual district Rotary conferences at Delhi, Goa and Dharwad – three different parts of India. The attendance at each meeting ranged from 2,000 to 3,000 – a great opportunity to create awareness in a large, educated segment of India. I spoke of my experience with raising a child with hearing loss in hopes of inspiring progress toward a nationwide early hearing detection and intervention program as well as national MMR inoculation.

I am grateful to my Rotary District 5320 for their support in my activities and hope others will become motivated to encourage India, now a world leader in technology and human resources, to recognize the great untapped potential in its many people with hearing loss. ■

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