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The Elizabeth M. Boggs
Center on Developmental
Disabilities changes lives

Turning Disabilities into Possibilities

By Lynda Rudolph

Photos by John Emerson

The day that Jonathan David Boggs was born in 1945, no one could have predicted he would become the catalyst that would inspire the launch of one of the most respected and recognized centers on developmental disabilities in the nation. Or that he would change the lives of thousands of people like him. David, as the family called him, was born with an umbilical-cord infection that resulted in mental retardation and cerebral palsy. His mother, Elizabeth M. Boggs, who until his birth was on the road to a career in mathematics and chemistry, shifted her focus to advocacy for the developmentally disabled.

Her influence as a policy maker and scholar became legendary and inspired the legislation that created a network of centers nationwide. Her involvement and contributions both locally and nationally challenged the conventional roles that those with developmental disabilities played in their communities. The Elizabeth M. Boggs Center on Developmental Disabilities, New Jersey's federally designated University Center for Ex-

cellence in Developmental Disabilities Education, Research, and Service, is aptly dedicated to her, and to fulfilling her vision of progressive social policy that supports individuals with developmental disabilities and their families.

Carrying on the mission of its namesake, who died in 1996 (followed by David four years later), The Boggs Center provides educational programs, technical assistance, consultation, and research to inspire others to value and promote the well-being of individuals with developmental disabilities. According to Deborah M. Spitalnik, PhD, professor of pediatrics and executive director of The Boggs Center, "We affect the community in two interlocking ways. We help enunciate a vision of full lives for people with developmental disabilities and their families, and we enhance the skills and capacities of practitioners, communities, and service systems to realize that vision. We recognize the contributions those with developmental disabilities can make in their communities as they lead meaningful lives."



Understanding the Diagnosis and Trends

Developmental disabilities are severe and chronic disabilities that originate in childhood, produce significant functional limitations, and extend throughout the life span of the individual. Conditions such as Down syndrome, Fragile X syndrome, cerebral palsy, and autism; metabolic disorders such as phenylketonuria (PKU); and degenerative disorders such as Rett syndrome are all classified as developmental disabilities. It is estimated that about 17 percent of all children have a disability or chronic health condition, and 2 percent have a serious developmental disability such as an intellectual disability/mental retardation, cerebral palsy, or autism. In the early part of the 20th century, those with developmental disabilities were feared and misunderstood, and institutionalization was a standard practice. But by the end of the century, attitudes had changed. Education and integration into the community emerged as trends that resulted in great successes.

Much of the education about developmental disabilities in New Jersey emanates from The Boggs Center. According to Michael Knox, PhD, assistant professor of pediatrics, and the center's deputy director, "People here are well grounded academically and have an impressive breadth and depth of expertise, but there is no ivory-tower mentality. We take our role seriously as a bridge between university thought and the community." One of The Boggs Center's hallmark community education offerings is an eight-part annual Developmental Disabilities Lecture Series, featuring nationally known experts, offered in central and southern New Jersey. Established in 1984, and funded in part by the New Jersey Department of Human Services' Division of Developmental Disabilities, the program has since gained a reputation for being the forum for forerunners in thought and practice innovations, and it attracts people from great distances.

Pioneers in Adding Value to Lives

Ellie Byra, whose son Matthew was born with multiple disabilities, began her relationship with The Boggs Center through the lecture series. “When I attended, I got a sense of vision for the future for Matthew that had until then looked bleak,” Mrs. Byra says. “They expose those who attend to new ideas and offer information and the tools to bring them to life.” Matthew had been in segregated schools until he was 11 years old. Mrs. Byra learned through the lecture series that there was a way for him to matriculate with his peers in a traditional school. With her advocacy and hard work, Matthew was the first child in New Jersey with severe disabilities to be totally included in a regular school environment. “Matt went to Hunterdon Central in all non-handicapped classes,” Mrs. Byra says.

Because of what Mrs. Byra has been able to do for Matthew, he and other people like him have a very different life. “As Matthew aged, the question arose about what his future would be like. Day care was not an option. We wanted him to have as normal a life as possible,” Mrs. Byra says. Today Matthew, who is 33 years old, is out in the community. He volunteers at Hunterdon Medical Center two days a week and works in the Raritan Cafeteria three days a week.

Mrs. Byra also believes that the lecture series and The Boggs Center’s educational efforts have had a huge impact on family members who have a loved one with developmental disabilities. “You learn how to deal with behavioral issues, how to understand what resources are available to you,” says Mrs. Byra. “Education is empowerment.”

Along with the lecture series, The Boggs Center is instrumental in bringing state-of-the-art practices to New Jersey. “The Boggs Center serves a unique role as a touchstone to give us balanced, person-centered guidance,” says Jennifer Velez, commissioner of the New Jersey Department of Human Services. “I feel it provides a safe space where we can bounce ideas off of each other. I know when I ask a question I’ll get feedback about a policy being considered that really takes the individual into consideration.”

Teaching, Training, Serving, Healing

Making faculty and staff available to serve as subject-matter experts, and on task forces and subcommittees, furthers the center’s mission to keep the dialogue going and the programs and thoughts about individuals with developmental disabilities evolving. By stimulating interest in what’s being done for those with devel-

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opmental disabilities, and by responding to a felt need, The Boggs Center raises awareness and interest, which in turn spawns a more intensive forum to take actions and solve problems. Last year alone, The Boggs Center conducted 838 activities, consultations, and advisory meetings with state and community agencies, school districts, and families. The faculty and staff serve on more than 20 national committees and more than 36 state and local committees to share best practices and work collaboratively to build capacity and create change.

One of the cornerstones of The Boggs Center’s educational efforts is the training it provides to students and residents in the Department of Pediatrics. All of the students in the required third-year pediatrics clerkship — most of



whom have had minimal prior experience with people with disabilities — spend 12 hours at The Boggs Center’s Seminar on Family Centered Care and Developmental Disabilities. First, there’s didactic study, during which the students’ own values, perceptions, and attitudes are clarified. Then a family member of a child with a developmental disability speaks about the family-centered-care approach. The most dramatic element — and for some students a career-altering event — is the component of the program during which students spend time in the homes of families who have a child with a developmental disability. The encounter gives the student an opportunity to see the child in the context of his or her family, talk with the family, and learn what physicians can do better to meet the challenges of those living with developmental disabilities.

Ginny and Stephen Bryant and their four-year-old daughter, Rachel, who has Down syndrome, are a host family for The Boggs Center medical students’ training initiative. Rachel typically meets and greets the students at the front door of the Bryants’ home and spends an hour

having a tea party with them. The students then join the family for dinner and, once Rachel goes to bed, have a conversation with Mr. and Mrs. Bryant. “It’s amazing to see the transformation of the students during the short time they’re with us,” says Mrs. Bryant. “Their expectations are blown away when Rachel makes eye contact and talks with them.” The Bryants agreed to participate in the program because they feel it is critical for medical providers to understand not just what Down syndrome children can’t do, but what they can. “It’s rewarding to leverage our influence on these students that could potentially have a ripple effect in the medical community,” adds Mrs. Bryant.

Erica and Steven Gendel and their son Joshua have also participated in the training initiative for two years. Joshua weighed just 650 grams at birth. His medical issues are significant, including severe cerebral palsy, seizures, vision impairment (he is legally blind), and Crohn’s disease. He has had more than 30 neurosurgeries, four gastrointestinal surgeries, and countless diagnostic tests in his young life.

As challenged as he is, Joshua is a sociable, happy child who refuses to let his medical and developmental challenges get him down. Although he's cognitively delayed, he attends school and does well in math. Mrs. Gendel feels that the work they do with medical students is valuable: "We want them to know what life is like on the other side of the wall. To be a better doctor, you have to be sensitive to all the issues people are facing." The typical interaction involves dinner with the family. "We pack a lot into that time at our house. At the end of the evening, we ask the students what they got out of being with us," Mrs. Gendel says. Some students give them hugs. Some shed tears hearing about and seeing Joshua, an outgoing, lively child who has been through so much. "In the end, we feel if we've made an impact on even a couple of students, to listen more, to see the big picture, and embrace a sensitivity, we've done our job," Mrs. Gendel adds.

At the end of the rotation, the students are asked to offer an evaluation of the experience. Among the comments (given anonymously), one was that, "it opened my eyes to a personal story of a disabled child." Another student offered, "I would hope every medical student was able to get this experience. I now feel more comfortable interacting with people with developmental disabilities and know what families like," and the person added that the experience would help the student "truly try to walk in the parent's and patient's shoes to understand their hardships and necessary changes in their health care." As to how the rotation will affect future dealings with families that include children with disabilities, comments included, "I learned to really listen to the family and that the families really appreciate physicians working as a team to provide the best care for their child."

There are other collaborations and programs that help provide care and education to those with developmental disabilities. The Boggs Center, in collaboration with the Department of Family Medicine and Community Health — and utilizing a grant from the Robert Wood Johnson Foundation and state funding — provides health care and a medical home to adults with developmental disabilities at the Family Practice Center. Family medicine residents care for patients with developmental disabilities throughout their residency. The Boggs Center has had a hand in making sure that children and adolescents with disabilities are prepared for meaningful adult life by working with school districts to provide behavioral support and educational and work experiences in the community. The center also is working with the state and provider agencies in New Jersey to ensure that children with significant behavioral disorders can live in the community.

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An Encouraging Future

One of the promising but challenging statistics is that those with developmental disabilities are living 90 percent longer. There is a growing need to serve these older populations. It requires a shift in thinking to build services and programs around people with developmental disabilities so that they can live and work in the community and age in place. "We are committed to promoting the understanding that people with intellectual disabilities are active, valuable individuals who can have a career, a social life, and make a contribution to society," Dr. Spitalnik emphasizes.

For David and Elizabeth Boggs, there is no legacy more fitting. **M**