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USE

MAGAZINE



The Future of
Health Care is Here
Morsani Center Opens

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COVER PHOTOS: ERIC YOUNGHANS,
USF HEALTH MEDIA CENTER
SCENE ON CAMPUS: JOSEPH GAMBLE

BY ANN CARNEY

Guiding Han

USF's Center for Autism and Related Disabilities helps optimize the potential of people with autism.

FOR NICOLE TORRES, A FIRST-TIME mother, the behaviors seemed odd at first—screaming at the sound of a barking dog, repetitive hand-flapping and paralyzing fear if he fell in sand at the playground. Odd, yes, but surely her 2-year-old son, Chase, was fine. Surely he was just a sensitive boy.

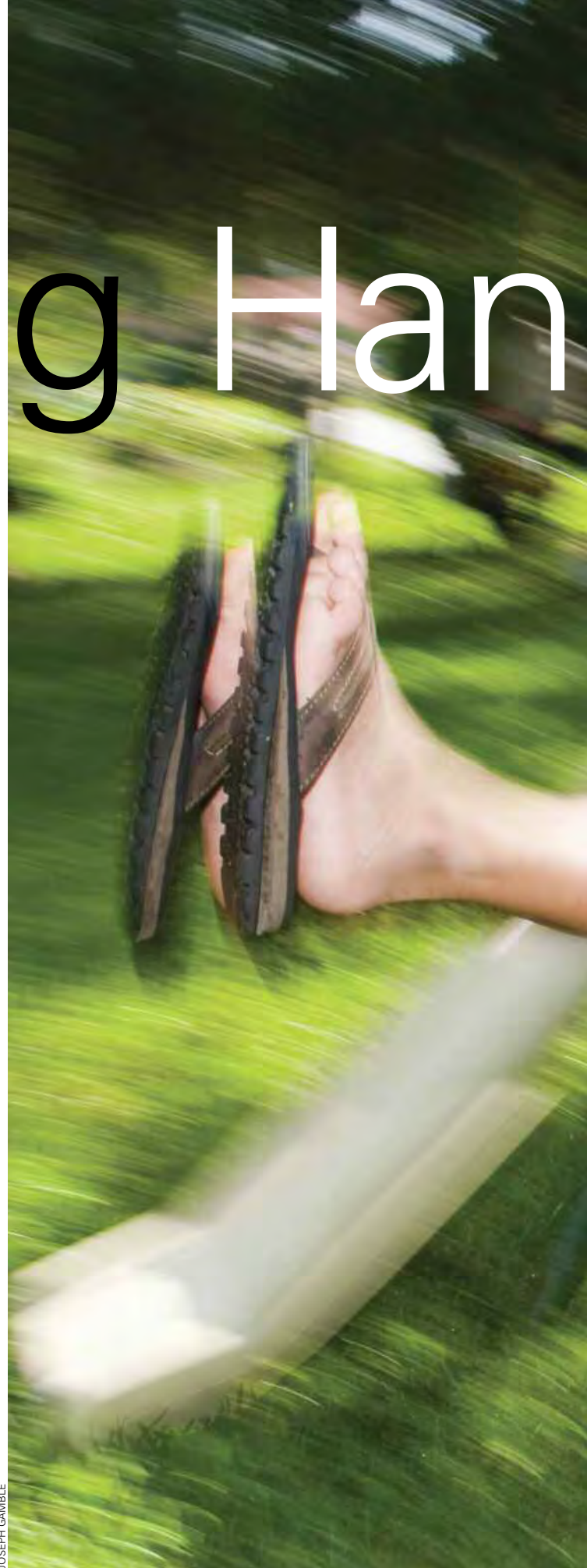
Or so she thought, until a pediatrician began to question Chase's inability to speak. And a speech therapist began to ask questions like: Does he put strange things in his mouth? Does he self-injure? Does he lick things? Did he have language at some point?

"I wondered, what does this have to do with speech," Torres recalls. "Then I began to research and realized these are the questions you ask when you suspect a child has autism. I panicked."

Torres, a single mother and 33 at the time, made an appointment with a neurologist, and then another. After extensive testing, her fears were confirmed. Chase was diagnosed with severe autism.

A developmental disability with widely varying severity, autism affects the brain resulting in communication, social and sensory dysfunction. The disability, which typically appears in the first three years of life, affects the way people perceive the environment and the way they act. Estimates suggest more than 400,000 people in the United States today are living with autism.

Determined to learn all she could about the neurobiological



JOSEPH GAMBLE



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Nicole Torres says CARD-USF gave her the tools to support the special needs of her son, Chase, who has autism.



JOSEPH GAMBLE

disorder and do everything possible to meet the special needs of her son, Torres gave up her executive job, moved in with a friend and applied for food stamps. She signed up for Medicaid to get Chase the speech, occupational and physical therapy he desperately needed.

“There was nothing I wouldn’t do,” she recalls. “One way or another I was going to get my son through this.”

At Early Steps, a local program for children up to age 3 with developmental disabilities, Torres was assigned a family resource specialist. That’s when she learned about CARD—the Center for Autism & Related Disabilities at the University of South Florida.

“My family resource specialist helped me to attend a CARD conference,” she says. “I was desperate for information.”

The annual conference to help participants understand the nature of autism and related disabilities is just one of the many services provided by CARD-USF, a community-based resource center serving children and adults with autism and related disabilities. Established in 1993 and funded by the Florida State Legislature, CARD offers instruction and coaching to families and professionals through training designed to optimize the potential of people with autism and related disabilities. CARD-USF is the oldest of seven university-based regional CARD sites and serves 2,200 families in 14 counties in southwest Florida. Its Web site, with links to information, resources, training events and special programs, has recorded more than 750,000 hits since May 2006.

Shelton Gilyard, CARD Consultant, demonstrates the use of visual tools with Hillsborough County School District Resource Teacher for Autism, Suzan Fine, as a third-grader looks on.

Center Director Dr. Karen Berkman says CARD provides services in four areas: direct assistance, technical assistance and consultation, professional training, and public education and awareness. Most importantly, she says, the services are provided free of charge.

For Torres, direct assistance began with a home visit by a trained consultant.

“She was wonderful; she listened to all of my concerns. She listened to the dreams I had for my son’s future and provided me with information, like the importance of using visuals,” Torres says. “She never worked with my son directly. It was more about giving me the tools so I could work better with him. It was such a needed support.”

That kind of assistance is exactly what CARD provides, according to Berkman.

“We help people walk through the first steps, to focus on right now, the things they are eligible for, what assistance they may need. We provide them with simple tools and strategies like breaking tasks down to the smallest steps and an endless database of autism-specific resources,” she says. “CARD is a place where you can go and tell your story and we get it, no matter what changes. And because we get it, we provide continuity over time.”

CARD does not offer treatment, diagnosis or crisis management. It builds in the training and technical assistance to enhance existing services and resources for people with autism spectrum disorders and their families.

When Chase moved into the public school system at age 3, CARD-USF was there, conducting classroom-based observations and offering strategies and suggestions like a visual schedule to help Chase understand and break down simple tasks. When social or behavioral concerns arose, Torres' consultant offered helpful information and strategies.

Torres was successful at using the learned interventions—interventions which made positive changes in their lives. Today, at age 7, Chase is in a regular education classroom earning straight A's. He doesn't have an aide. "CARD-USF has played an important role in his success," says Torres, now a CARD-USF Constituency Board member and a family resource specialist for Infants and Young Children of West Central Florida and the Early Steps Program. "I could go on and on about CARD."

In addition to providing direct assistance to parents like Torres, CARD-USF provides training and consultation to schools, employers, health care workers and agencies that have direct interaction with individuals on the autism spectrum. Training is focused on awareness, skill development and capacity building.

"CARD is action," says Holly Sutherland, Low Prevalence Facilitator for Polk County Public Schools. "They come out and support the teachers. They give us strategies to use for different behaviors and different strategies for different students on the autism spectrum. They also come out and support the parents. They'll come to the home and see what behaviors are happening or what support the parents need and give them help with that."

Cindy McKinnon, ESE Program Specialist for Sarasota County Public Schools, was introduced to CARD-USF early on when she called for assistance with a particular student. "They came in and provided all kinds of services to us," she recalls, services the district continues to use today. "CARD has assisted us on providing training to our staff coming into our schools—helping individual teachers as well as groups of teachers, and we've also sent teachers to training in the Tampa Bay area that CARD has provided."

An annual summer institute offers training to new and experienced teachers on research, innovations and effective programs for students. And, through a special program funded by the Florida Department of Education, CARD provides training and technical assistance to teachers to enhance the educational program for students with autism spectrum disorders.

"People with autism have much more going on inside

than they are able to communicate or that people give them credit for," says Berkman. "They are intelligent. They want to have relationships. They can love people; they want to engage with people."

But despite their abilities and desire to be included, children with autism are often left out. Through various projects and initiatives, CARD-USF is working to change that.

Last summer, working with the Hillsborough County Parks, Recreation and Conservation Department, CARD consultants visited six local camps to provide instruction and best practices for including campers with autism. And, in collaboration with the City of Tampa Parks and Recreation Department and a parent support group, CARD helped design an after-school social skills and recreation program for children with autism spectrum disorders at the Loretta Ingraham Recreation Complex. CARD consultants provided weekly training, materials and strategies for staff counselors.

"It's time that everything is available to everyone," says Berkman, who in March was named to a state-level task force on autism spectrum disorders by Florida Governor Charlie Crist. "It doesn't take a lot to make it work."

While Berkman and her staff have made significant inroads, she says adults with autism have great difficulty finding meaningful and gainful employment. About 85 percent of people with autism are unemployed.

"Part of the problem is the barriers that exist to people with autism accessing opportunities," she says. "People with autism can be reliable, motivated and very accurate. Employers are frequently searching for individuals who can focus on quality outcomes and can be long-term workers. Our constituents can be those successful employees with the right set-up and supports."

That support can be multi-faceted, according to Berkman. To help adults with autism transition to work, for example, CARD consultants may conduct a worksite visit. By gaining a comprehensive understanding of the job and its responsibilities, the consultant can break down every aspect of the job and help ensure the constituent's success.

But it takes a willing employer.

"We need to change the mindset. We must dispel the myths that exist so people with autism can be offered opportunities to be full citizens of our communities," she says. "We need to imagine the possibilities of what people with autism can do," says Berkman.

For Torres, that's not a problem.

"My vision for Chase is to one day be completely independent—to hold a job, to have his own place and to be happy. I want him to live a full and productive life," she says. "And I'm never going to give up on that." ■