BRAIN DISORDERS

BRAVING THE UNKNOWN

BY SUSAN G. LAUERMANN, APR & ANDREA POTOCZNY-GRAV, M.ED., CBIS

Famous American author Isaac Asimov once wrote that “the human brain is the most complicated organization of matter that we know.”

For parents Renee and Jake Thompson of Westborough, Mass., these words resonate on a profoundly personal level. Eleven years ago, Renee gave birth to their beautiful son, Zachary. Like most mothers and fathers, their hearts were brimming with grand plans for their child’s future.

However, as Zachary began missing typical milestones in infancy and into toddlerhood, the worry set in that there could be something wrong with their son.

Today, Zach is a vibrant, funny fifth-grade student at the May Center for Education and Neurorehabilitation in Brockton, Mass. But his path to the school, and through his first 10 years, was a circuitous one. This is the story of one family’s relentless pursuit to find people who understand Zach – and his needs – and how the right fit can make all the difference.
GETTING A DIAGNOSIS

Renee and Jake started seeing red flags before Zach reached his third birthday. Zach had extreme difficulty controlling his emotions and actions. He was often aggressive towards others, and could be destructive of his surroundings.

It would be a grueling five-year marathon for the family, involving neuropsychiatric consultations and evaluations, brain scans, conflicting test results and information, and changing medications. They saw a number of experts before the Thompasons finally got a definitive diagnosis.

“When Zach was eight, we were told that he has partial agenesis of the corpus callosum, delayed myelination of subcortical areas, and cerebellar atrophy — a rare brain disorder,” Renee remembers. All of these conditions affect the message-delivery center of the brain. Motor and sensory skills rely on how well the information is processed and whether it gets sent to the other parts of the brain.

In addition, subsequent and separate diagnoses of attention deficit hyperactivity disorder (ADHD) and nonverbal learning disability were also confirmed. “I have a degree in early childhood education so even though the medical terms were scary and unfamiliar, I knew something about child development,” Renee says.

“I knew enough to keep pushing for information and it’s something I would encourage any parent to do who finds themselves in similar circumstances,” Renee adds.

FINDING THE RIGHT FIT

Armed with this new information, Zach’s parents removed him from his local public school and enrolled him in a private education school close to home. Unfortunately, Zach’s needs went beyond what that program could offer.

“May Institute’s name came up as a possibility, but we had concerns about the distance away from our home,” Jake remembers. “But we went for a visit and, within the first 10 minutes, they helped us understand more about my boy than all of the other experts combined,” Renee says.

Zach’s first two weeks as a student there gave staff an opportunity to observe his behaviors firsthand. Whenever a new student is admitted to the school, staff members create a “baseline” by recording an initial set of data points. The information they collect may include descriptions of behaviors to address, the reasons for (or “function” of) those behaviors, and what conditions seem to trigger them.

With the benefit of this important information, staff members are then able to monitor and measure the effectiveness of a prescribed course of treatment and therapy by comparing subsequent data points with the initial ones. This data-based approach is one of the hallmarks of Applied Behavior Analysis, or ABA. [See sidebar for more information about ABA.]

From that point, the team works with the student’s medical professionals and family to develop an Individualized Education Plan (IEP) for the student. An IEP is a document that outlines special education and related services that schools must provide to eligible children. It includes measurable goals and outlines services the child will need to succeed in school.

Strategies for Parents
New to a Brain Disorder Diagnosis

BY GARY PACE, PH.D., BCBA-D

Adjusting to the reality that your child or loved one has a brain disorder is nothing short of formidable on many levels. Just as no two treatment plans are exactly alike, neither are the strategies for helping families remain functional, healthy, and strong. However, the following tips may be helpful to you in regaining your bearings in the days ahead.

• Don’t become attached to a specific outcome. With many brain disorders, including Zach’s rare brain disorder, it is nearly impossible to predict how the brain will compensate for the deficits associated with the disorder. Every individual is unique, with multiple factors and diagnoses at work. This differs from other types of brain disorders where there are specific milestones that can be predicted and achieved. The secret is to focus energy on the day-to-day victories and work to get to a mental space where you can be “okay” with letting the situation play itself out.

• No extra points for going it alone. Financial and community resources are available, and many people have extended family and/or social networks. When you (or your family member) are losing the ability to function effectively as a parent, in school, or at work, don’t be afraid to reach out to a friend, relative, or professional therapist for support. You can’t be the person, spouse, employee, or parent you need to be if you are not in a healthy place.

• Applied behavior analysis (ABA) can be very effective in addressing the educational and behavioral needs of children with brain disorders. ABA methodology includes teaching in small steps, using positive rewards, providing structured assistance, finding that assistance as soon as possible, offering lots of opportunities to practice, collecting data to assess progress, and making frequent revisions and modifications as necessary. Educators and clinicians using ABA procedures for students with brain disorders work particularly hard to set the occasion for positive behavior: This means focusing on those things that make it easier for the student to learn and to avoid problem behaviors.

• You are your child’s best advocate. For many students, behaviors in the classroom are not always generalized at home at the same pace. In these instances, be sure to consult with your teacher/provider to determine whether home-based services would be a beneficial addition to your child’s IEP.

ABOUT THE AUTHOR:

Gary Pace, Ph.D., BCBA-D is senior vice president, Neurorehabilitation Services, May Institute; Supervising psychologist, May Center for Education and Neurorehabilitation
ACADEMIC AND SOCIAL CHALLENGES

Academics and socialization were identified as two key areas of focus for Zach. These are typical challenges for children who share Zach’s group of diagnoses. “When Zach first started at the May, we just wanted him to feel successful and to feel a part of the group. One would think that is pretty easy and something that can happen naturally, but nothing comes easy for Zach,” Renee says.

“Zach’s teacher was very open and honest and incredibly helpful when describing how and what they were initially implementing for Zach. It was such a change for us because our previous experience in other settings was limited to stressful phone conversations about what we, as his parents, were going to do about his behavior. All of a sudden, that responsibility had been lifted and in the hands of professionals with expertise in brain disorders.”

Jake remembers, “Within such a short time, our worries disappeared as we began to see things in Zach that had not been evident in a long, long time – like self-esteem. He was beginning to feel proud and happy.”

AN EVOLVING FAMILY DYNAMIC

During the 17 months Zach has been in the program, the Thompsons have been amazed by their son’s transformation. “I once told Zach’s occupational therapist that I would rather lose a finger than to even attempt getting Zach to write anything at home... that’s how bad and stressful it was,” Renee says. “Yet now he is bringing work home, copying words, writing notes, making comics, and coloring!”

Not only has Zach’s academic performance improved significantly, he has made dramatic strides in keeping himself safe and controlling a previous pattern of intense aggressions. “There is a kindness, generosity, consistency and patience that is fostered at school that has helped Zach to become more comfortable with himself,” Jake remarks. “He can make you feel like you are the most special person on the planet – inherently very loving and compassionate – and he is always working on a ‘plan’ to do something for someone else.”

Zach and his younger sister, Abby, are 30 months apart in age. “I can remember one night, early on, when Zach was having one of his frequent meltdowns. Abby, who was seven years old, was brushing her teeth as I walked into the bathroom,” recalls Renee. “She looked up at me and said, ‘I can’t take this anymore. I just can’t.'”

Today, Zach and Abby are each other’s best friend, although have their ups and downs like all siblings. Jake explains, “Our whole family dynamic has continued to positively evolve because we are so much more supported now, and helped to feel accepted and not alone. The amount of knowledge that we have acquired in the last year and a half has helped to make the daily struggles more manageable.”

Renee adds, “We are all at such a different level of understanding now, not only about what Zach needs and how we can best support him, but about how to respect each other’s needs as members of a family. We all communicate differently, but each of us knows we are here for the other in whatever way we need to be.”

LESSONS LEARNED ON THE JOURNEY

Any type of stress tests the best of relationships, and raising a child with special needs can sometimes break a marriage apart. Renee and Jake are thankful that, through it all, they have remained solid. “We are polar opposites, so perhaps that helps,” Jake chuckles. “But when you’ve been together for so long – over 20 years – and through so much, you learn how to work well together. And we do.”

Jake explains that what has helped him throughout the journey is getting away from the idea of a ‘fix.’ “Like all parents, you have lots of questions of what the future will bring for your child. But today we are much more hopeful. We celebrate where Zach is, and who he is, today,” Jake says. “His academic skills have grown exponentially. He’s a social butterfly in school. And he is trying as hard as he can to grow and mature, despite the tough challenges he faces every day.”

Both parents agree that you are your child’s best advocate; you should follow your gut. “Unfortunately, this approach often translates to trusting no one and bullying your way through the process until you find the best solution,” says Jake. “But that would be wrong. You should trust the people around you who are trying to help, but educate yourself and never just accept what you are given,” he continues. “If it doesn’t seem right or isn’t working, keep asking, keep evaluating, and keep trying. There could always be something else going on and you owe it to your family to know what it is. You are the expert on your child. It may not be easy, and you may not even understand what you are being told, but make the effort and put the time into it to learn.”

MOVING FORWARD

For every child diagnosed with a brain disorder or brain injury, the journey is unique. But, in the words of the Thompsons, comfort can be found in universal truths.

“It’s the silence that keeps things like fear and judgment running amok. Among the many things that we have learned from our son is to live for right now. Share your experiences, and be open and unafraid of what people might think or say. You may just be surprised with the amount of acceptance, understanding, love and support you receive when you do.”

ABOUT THE AUTHORS:

Susan G. Lauermann, APR, is a director in the Office of Communications at May Institute. She has been a senior-level communications professional for more than 20 years.

Andrea Potoczny-Gray, M.Ed., CBIS, is executive director of May Institute’s May Center for Education and Neurorehabilitation.