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THE
**AUTISM
AWARENESS**

ISSUE



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AUTISM AWARENESS

HOME AND AWAY Brandon, Bobby, and Donna enjoy a family vacation to London.

It All Starts at Home

BRANDON'S STORY

BY SUSAN G. LAUERMANN, APR,
AND BOB PUTNAM, PH.D., BCBA-D

Brandon was diagnosed with severe autism in 1981. Parents Bobby and Donna, and stepfather Marshall, still remember the pain they felt in learning of Brandon's diagnosis and then hearing the heavy, hollow words from the diagnostician that followed. "Brandon will never acquire language skills. Never be able to go to school. You should immediately consider placing him in an institution."

Fast-forward three decades. Thirty-three-year-old Brandon is a man in his prime. He is truly the whole package – joyful, handsome, fit, articulate, compassionate, employed, thoughtful, social, easy-going, talented, loving, and well-loved.

Brandon also has the unique distinction of being one of the original graduates of May Institute's Home-Based Therapy program for children with autism back in the 1980s. At that time, the program was part of the Institute's original seaside school in Chatham, Massachusetts.

The decision to have him receive services is one that Bobby, Donna, and Marshall believe saved their son's life.

Connecting the Dots

For Donna, initially there were no real outward signs in her son's development that set off any alarms but, rather, a mother's intuition that something was different about Brandon.

"No one was talking about autism 30 years ago so I had no reference to autism," Donna recalls. "As a toddler he played differently than the other children. He was very ritualistic and entirely happy pulling bark off a tree for hours on end," Donna recalls.

But both Bobby and Marshall had prior experiences with autism that had triggered signs of concern. Much earlier in his life, Bobby had met twins who had been diagnosed with autism. Years later he learned that those were the sons of Dr. and Mrs. May, the founders of May Institute. When the Mays opened that first residential school in 1955, it was called the Parent's School for Atypical Children. It was one of the first such programs in the country.

"My experience was that if you had autism, you were shut out from the world, incapable of being aware of anything around you. Autism scared me," remembers Bobby.

Without having the language skills to communicate his needs, Brandon was easily frustrated. He was prone to long hours of

tantrums, screaming and yelling, and refusing to go to bed. Impulsive behaviors would often put him in unsafe situations, and he became extremely anxious when anyone tried to touch him. Diet and nutrition were also issues, as Brandon would only eat pasta, Cheerios, and chocolate.

Bobby remembers the thoughts that were racing through his head during those early days. "I'm the kind of man that is used to fixing things. So, my first instinct was to find a way to fix it," he says. "Of course I couldn't, and soon realized that the help Brandon needed was different from what I thought he needed."



Finding Hope Through Partnerships

After a few false starts with teaching techniques that were not yielding the results Donna was seeking, the family approached May Institute when Brandon was five years old.

Brandon began receiving therapy services in his home, based on the principles of applied behavior analysis, or ABA. These services helped Brandon develop communication, social, behavior, and self-care skills. Every teaching program included training for his parents and siblings to ensure that each member of the family could support the skills Brandon was acquiring.

Bobby. They were absolutely committed to doing everything I asked in order to reinforce the supported learning environment we worked so hard to create for Brandon."

Research shows that children with autism spectrum disorders (ASD) tend to have the greatest success when parents are able to replicate the same strategies that a behavior analyst uses. The partnership between therapist and family is critical, and parents can be trained on the specific strategies that are most effective and motivating for their child.

"It's not an easy process, but Brandon's family did it," adds Charlene. "As a result, Brandon has had the opportunity to explore his appetite for learning, develop self-esteem, give of himself to others, and find joy."

Charlene Carey, 30-year special education veteran and Brandon's behavior therapist at May Institute at that time, currently teaches at an elementary school in South Yarmouth, not far from where she and Brandon's family met. She was, and still is, an important person in Brandon's life.

"What we, as therapists, bring to the table is only one factor that contributes to a child's success. In Brandon's case, that success has been nothing short of phenomenal," Charlene explains. "A huge amount of credit belongs with Donna, Marshall, and

Home-based Therapy for Children with Autism Spectrum Disorders

Home-based therapy, based on the principles of applied behavior analysis (ABA), provides meaningful learning opportunities for children with autism spectrum disorders (ASD) to master critical skills in their home or other familiar environments. These one-on-one therapy sessions can typically take from several hours to 20 hours per week, and are always based on a highly personalized treatment plan.

A critical component is increasing the number of teaching opportunities (interactions) for each child and using data-based decision making to increase each child's skills and competencies. Early intervention services based on ABA have been found to be most beneficial when they are provided as early as possible and supervised by qualified staff (usually by a behavior therapist who is Board Certified in Applied Behavior Analysis (BCBA)) and delivered by a direct therapist who has training in ABA. Often these services are delivered before a child enters school.

Children with ASD often manifest deficits in communication and social interaction as well as functional skills. They require additional support with language development and communication, social skills and imaginative play, self-care, pre-academics/aca-

demics, and mastering skills that allow them to communicate their needs and desires in a way that decreases their need to resort to challenging behaviors.

COMMUNICATION/LANGUAGE

For children with limited communications skills, therapists not only work on encouraging verbal language, but also on teaching them non-verbal ways to communicate their needs. This can include activities as fundamental as teaching a child to use eye contact or point to share experiences (joint attention). It can also include teaching a child complex skills like mastering language to express thoughts and feelings.

Social Interaction and Play Skills

Deficits in social interaction with adults and peers require specific evidence-based training to teach these important skills. Direct instruction in these areas creates a natural bridge to more advanced forms of sharing and relationships. These skills are typically taught by using interactive toys, role-playing, or peer and sibling modeling.

REDUCING PROBLEM BEHAVIORS

It is important to carefully assess the environmental triggers that lead to chal-

lenging behavior, including outbursts, tantrums, self-injury, or aggression. Therapists also spend significant time learning exactly what motivates or causes the individual to engage in the problem behavior. They also determine what is most rewarding, or reinforcing, to each child, whether it is a hug or tickle, verbal praise, or a favorite toy.

The formal term for these investigations is a functional behavior assessment, and it is a necessary first step in developing a behavior support plan. Once finalized, the plan may include recommendations for modifying the environment, directly teaching replacement behaviors that will help the child gain what he/she wants appropriately, and providing positive feedback or rewards for appropriate behaviors. These are extremely effective strategies for reducing challenging behaviors.

PARENTAL INVOLVEMENT

As seen in Brandon's story, active involvement by his parents helped maximize his success. A critical component of home-based services is teaching family members better ways to support their child's development.





FAMILY TIES Brandon with his sister Shannon and brother Marshall Jr. *Opposite page:* As a little guy, Brandon was always curious about life.

Getting to Know Brandon as an Adult

Everyone who knows Brandon associates him with a sense of joy and sense of self that are quite inspiring – this is a direct reflection of Brandon’s outlook on life. “It is important to me to be a good person,” he explains. “Treat others well. Be helpful. Spend time with my family and do things that make me happy.”

Keeping himself in shape and running marathons, astronomy, reading history books, watching action movies and anything that spins, working at the store, collecting objects made of glass, listening to music, and bowling are just a handful of things that Brandon enjoys.

Conversation is another. Social nuances are typically challenging for many individuals with an ASD to recognize, but that has little effect on Brandon’s social skills and ability to engage with others. Bobby describes Brandon as “astonishingly articulate,” which has endeared him to all those who meet him.

“He uses his charm to find a way to direct a conversation with someone to his area of interest. It really is quite remarkable,” says Bobby.

For example, Brandon enjoys spending time with his dad, Bobby, at his restaurant, mingling with the customers. He is also fas-

cinated with fans. Bobby explains, “Brandon will start by asking someone whether they have a car. The person will say yes. Then, ‘So what color is it?’ The person responds. ‘Two-door or four-door? Leather or fabric seats? Is the engine in the back or front of the car?’ After getting an answer, Brandon will ask, ‘Doesn’t the engine get hot?’ The person answers yes, but there are coolants, and such. And then Brandon will get to the place he wanted to focus on from the beginning. ‘What about a fan? Does the engine have a fan?’ ‘Well, actually it does,’ will be the reply. Brandon’s smile broadens as he realizes the conversation has come to the place where he wanted to get to all along. ‘How many blades? What’s the RPM...?’”

In more complex, emotional situations, Brandon will understand that people are experiencing strong feelings, even if he doesn’t always comprehend the subtleties. Marshall adds, “Even though he may not always fully understand a conversation, his innate sense of compassion picks up on the emotions of others. For example, at dinner one night, he said to Donna and me, ‘I am sensitive to the fact that [this issue] is hard for you.’”

With a smile big enough to light the Eastern seaboard, Brandon’s ability to connect with people and desire to be helpful to others also shines at the local market where he works.

“One day there was a customer in line with her little girl. The girl was crying and upset,” Brandon explains. “There was a big container of detergent. I think it was bothering her. I asked her if she wanted me to take it out to her car and she said ‘yes.’ I did and she stopped crying.”

Over the years, Brandon has also demonstrated profound and prodigious capacities in the areas of math and memory. “He is truly amazing,” Marshall says.

But those accomplishments take nothing away from the rush of joy for his mother, father and stepfather when Brandon first uttered the words “I love you” or cuddled up in their arms, after years of being non-verbal and being deeply traumatized by any physical contact.

Times of Adversity Allow You to Figure Out what is Important

For the past 27 years, Brandon has spent every weekend with Bobby on the Cape. “Donna has been relentless in making sure Brandon has been given every opportunity to succeed; she’s been incredible. We were all friends first, and the experience with Brandon has only brought us closer,” Bobby says.

“To be the kind of person – the kind of parent – you really want to be for your kids, you have to learn to let things go that no longer serve you. Remind yourself what’s



WHERE THE HEART IS Donna, Brandon, and Marshall spend a quiet afternoon at home.

truly important and reduce the days to the one you are living today.”

“I have loved Brandon from the moment I met him,” says Marshall. “Each of us has our own unique relationship with Brandon, but he and I have always had the ability to connect in a

way that is different from his other relationships. I like to think of myself as the ultimate authority on Brandon,” he laughs.

Both men credit Donna for being the driving force behind the man Brandon has become. “There was never a choice to be made in my mind of how we were going to make it work; you just make it work – whatever it takes,” Donna says. “When it’s your child, everything else falls away except the goal to get them what they need.”

“Staying close as a unit has always been important to me and to Bobby. We wouldn’t have it any other way. We’ve each been there for the other in ways that have drawn us closer and made each of us appreciate what it means to be a family,” Marshall explains.

When You Think You Can’t, You Can

Brandon shares his parents and Marshall with siblings Shannon, 35, and Marshall Jr., 24.

The family acknowledges that with the passage of time, the tough stuff tends to fade and be replaced by moments in time that will always be a testament to how the love of family can move mountains.

Marshall reminds all families, “Things can work out much better than you can ever imagine; in our case things worked out way beyond what we thought was possible.”

And, Brandon reminds us, “I’m happy just the way I am.”•

Note: In a future issue of EP Magazine, readers will hear from Brandon about growing up with autism and life as an adult with ASD.

ABOUT THE AUTHORS:

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