

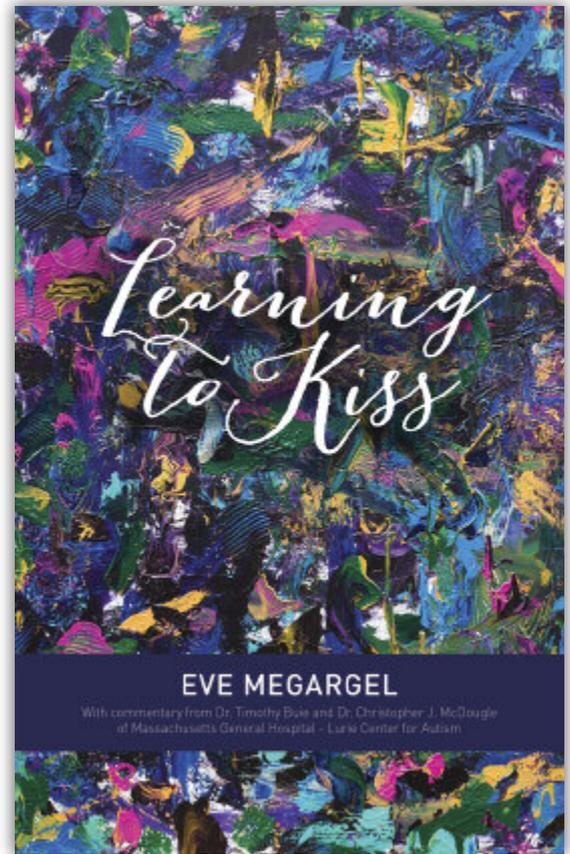
Learning to Kiss

JANET MENDELSON **writer**

billy megargel was an energetic two-year-old boy when he began losing his ability to speak. The 50 or so words that he knew slipped away and his developmental skills plummeted. Still, it took time for his parents, Eve and Matt Megargel, to absorb the life-changing news that came with a diagnosis of Autism Spectrum Disorder (ASD), a wide range of neurodevelopmental disabilities that affect behavior, social interaction, learning styles, and skills. Billy's doctors determined he had a severe form of autism. The consensus was that he would make limited educational progress and that his ability to communicate with others would be rudimentary at best. The Megargels refused to accept prevailing assumptions. From that point on, Eve became a full-time advocate for their son.

Today, Billy Megargel at 26 is an artist and musician who enjoys gymnastics and yoga. Using visual communication tools, including a computer tablet loaded with specialized software, he enjoys the give and take of relationships with teachers and those he loves. A talented painter in the abstract style of Jackson Pollock, his canvases reflect his emotions, exploding with color and movement. His work has been cited by *The Boston Globe* art critic Sebastian Smee and exhibited at Lesley University, the Laughing Dog studio in Wellesley, and Starbucks. He has permanent installations at the the Lurie Center at Massachusetts General Hospital and Jewish Family & Children's Service in Waltham. He lives with his parents in Weston.

Eve Megargel's new memoir, *Learning to Kiss*, describes her son's typical days and life-threatening moments over his first 25 years. She tells Billy's story of struggles and victories as well as how autism impacts family members and what is possible with hard work—Billy's, her own, and others'. For five especially painful years beginning about age 16, Billy had severe medical problems frequently associated with ASD. Time and again, there were



COURTESY OF INFINITY PUBLISHING

books “struggles and victories”



top: Billy Megargel bottom: Eve Megargel

road blocks created by often well-intentioned medical personnel, teachers, and specialists. During summers and when he was no longer able to attend an alternative school, she found tutors to work with him at home. According to Megargel, usually the best teachers are experts but don't necessarily arrive knowing much about autism.

I met with Eve Megargel in the contemporary barn that is Billy's home school. In many ways, he is fortunate. Over the last 10 years, his parents designed and built an outstanding facility in their backyard to address his ongoing educational and wellness needs. Moreover, his childhood paralleled the development of personal computing. Early on, they gave him a simple computer and taught Billy to point to pictures and words as a replacement for speech. Pages of voice output were recorded by his brother, Ben, who is three years older. Gradually Billy learned to use the computer to convey his basic needs.

As technology advanced, so have his skills and interests. From learning correct yoga positions to planning his special Saturdays



METZGER_STUDIOS

books “so much courage and compassion”

with his dad, Billy now uses a Panasonic Toughbook® loaded with Speaking Dynamically Pro—interactive software that turns a computer into a speech output device. The rugged tablet, built for police and emergency use, is sturdy, well-suited for the physically active young man who carries it everywhere on a heavy duty strap around his neck. If the first Toughbook fails, he has a second tablet as backup. At other times, he uses low-tech printouts. These options give him a voice.

In March 2014, the Centers for Disease Control and Prevention (CDC) released a study indicating approximately 1 in 68 children had ASD. But according to Eve Megargel, when Billy was diagnosed in 1992, it affected one in 10,000. About 25 percent are nonverbal.

“If I talked about it in 1992, nobody knew what I was talking about,” she said. “The cultural reference point was probably [the 1988 movie] *Rain Man*, the skewed, savant understanding of what autism

was as a disorder. Most of these individuals were not in schools or out in the communities. They were usually in institutions of some sort.”

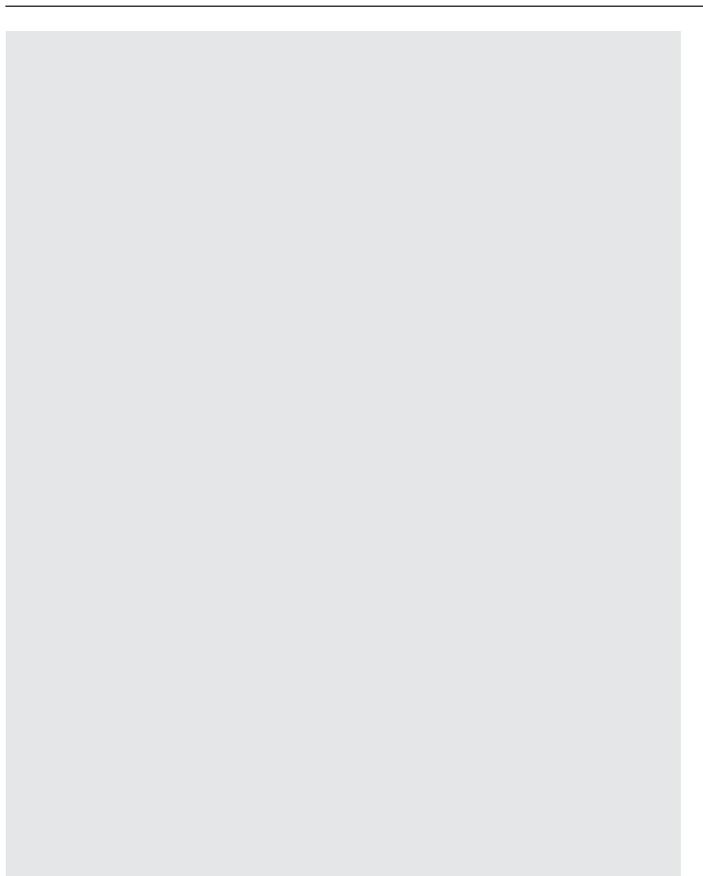
Billy’s home school is a sunny, well-appointed barn with studio space that any student of art and music would envy. There is a fitness area complete with a trampoline. For weekly yoga classes, pictures attached to boards with Velcro® hang on the walls so Billy can ask about correct posture and receive guidance. Music classes and jam sessions also use modified sheet music so he can follow a score, beating rhythms on drums or rippling tunes on an African xylophone. He uses cards to compose his own music while also learning classical notation. Everything is impressively stocked and well-organized.

At the barn’s rear is Billy’s art gallery with high-tech lighting and white walls that recall those on Newbury Street. Dozens of his completed canvases are displayed. Hundreds more are stored by size on open shelving. A few are his interpretations of works by the masters.

“Billy is all about expressing himself,” said Megargel with evident pride. “As an artist, he works in the moment, in the zone. His ability to use paints and tools is organic. He expects to paint every day.” A petite woman with a mix of energetic, no-nonsense and bohemian vibe, she contends that what many people call ‘behaviors’ are actually communication break-downs that those with autism experience.

As a young child, Billy was robust, said his mother. “Nobody could have predicted he would have critical health issues for five years. It could have been much worse but because he had a communication system and partners who knew how to use it, he was able to get into an ambulance multiple times, to go under anesthesia multiple times, and tell us what he was going through and heal multiple times.”

Everyone wants to connect, said Megargel who emphasized that her son has great strengths and significant deficits, but he is not exceptional. He is too vulnerable to be alone. Her stated goals now are to expand his community of peers and help him be as independent as possible. Out of their shared experiences, she created Voice Colors®, a communication resource model that since 2012 she has taught locally and shares with audiences of healthcare providers and parents of





- **LEARNING TO KISS** by Eve E. Megargel is available from Amazon in paperback or for Kindle.
- **WWW.VOICECOLORS.ORG** has a link to the documentary film *Voice Colors® — Billy's Story* and information on the Megargel's communication resource model for individuals with autism.
- **VISIT** www.wmmartgallery.com to see Billy Megargel's paintings online.

autistic individuals across the country. It is the subject of a one-hour documentary film available on her website.

“People who are well-meaning tend to look at the Billys of the world as separate, as non-communicators,”

she said. “The goals they set for them are ones of compliance rather than education. They expect them to follow directions rather than teach them how to ask questions.

“When Billy was very sick, we saw many medical professionals, social workers, and educators. Even though they had the best of intentions most of the time, they really still looked at Billy a certain way. They saw him as a non-verbal young man with autism, end of story,

effectively cutting off interaction. Yet this young man was exhibiting so much courage and compassion, such forgiveness. I needed to flesh out what they were seeing so that one day, if they read this book, and they interact with someone like Billy, they might rethink how they do that.

“Individuals with autism are not invisible. They have a voice and need access and education in terms of communication. It will not only make their lives easier but also the lives of those around them.” **WW**

