



## Spectrum Spotlights

*Though these are challenging times, we hope these stories offer a look into the many diverse perspectives in our community, and provide inspiring and uplifting content when we need it most.*

### **Meet Matty W.**

At Autism Speaks, we take pride in sharing stories from our community and providing a platform for people with autism and their families to provide unique perspectives about life on the spectrum. We celebrate individuality and diversity, and aim to recognize both the triumphs and the struggles of people from all walks of life.

Earlier this year, as we celebrated 15 years of

progress with a reimagined look, our president and CEO Angela Geiger said it best:

"Over the years, we have heard from the vast and diverse autism community from our supporters to our critics, and from those whose autism is their greatest strength to those for whom autism can be a daily challenge. [We aim] to highlight the depth, breadth and infinite differences along the autism spectrum and to show our commitment to listening, evolving and reflecting those we serve."

The story of 28-year-old Matty W. from Western Pennsylvania encompasses the highs and lows, struggles and successes that often accompany an autism diagnosis. Matty's journey hasn't been easy - in fact - his dad, Mark, says it's been quite difficult since the youngest of his three children was diagnosed in 1994 at two and a half years old.

Through even the toughest times, Mark and his family have been Matty's biggest cheerleaders and support system, advocating for him and fundraising in support of Autism Speaks and the life-changing research that can lead to a better life for Matty and other people with autism.

"I'm just a regular guy - a teacher in a small town - but my family and I have raised more than a quarter of a million dollars for Autism Speaks over the years. We've never missed a Walk in the Pittsburgh area and plan to be there for as long as we can. Not only does it give us a sense of community, but I truly believe there's still so much to be learned about autism. I know there's a lot of research being done by really smart people, especially in the biomedical field, so I'm hoping they find things that can improve Matty's life. There's more work to be done and we're going to do whatever we can to pitch in."

Mark says although Matty can't express himself with words, he knows that his son takes pride in walking beside his team, Marchers for Matty, on Walk days. He always sees the biggest smile on his face when they join the thousands of other families in the greater Pittsburgh area as they walk in unison towards a brighter tomorrow.

"We work and fundraise all year to prepare for the Walk. We wear the matching shirts and make a day of it. Walk Day is a celebration of hope for my family. We have over 100 friends, family, students and colleagues join in a sea of others walking for a better life for Matty and others like him. It's one of the best days of the year."

[Learn more about Matty and his autism journey](#) through the words of his dad, Mark, in this Q&A:

### **What spurred you to seek a diagnosis for Matty?**

Matty appeared to be developing normally up until about 18 months old. His language then began to regress noticeably. He seemed to become more distant and detached. We discussed it with his doctor and he suggested an auditory



Matty W. cutting grass



brain stem response test and then a full evaluation a full day at the Developmental Center at Children's Hospital in Pittsburgh. At the end of the day, all the professionals including a speech therapist, occupational therapist and developmental psychologist gathered with us in a circle and gave the diagnosis. It was the early 1990s and there was little attention given to autism. I was not sure what it actually

meant to be autistic. Nevertheless, we were confident we could get Matty the best medical care and get him better. We had no idea how little was known about autism and the limited services available to families at the time. When we left that meeting, we started the fight to get Matty the best treatments, therapy and supports available with the hope of giving him every opportunity at a "normal" life. We have not stopped in that fight.

### **What thoughts first ran through your head when Matty was diagnosed?**

My first thoughts after hearing the word autism associated with Matty was a belief that we could get him help. Beyond that, I was just numb to it all, honestly.

### **After you received the diagnosis, what were the next steps to getting your son the services and supports he needed?**

We initially registered him with a mental health base unit. There are several to choose from and this government funded agency assigns you a support service coordinator. This coordinator assists with helping the family access all support resources available to help with social, language and life skill development. Matt received medical assistance due to the dual diagnosis of mental health and intellectual disabilities. Initially, Matt was assigned to an Alliance for Infants support group because he was under age of three. This group consisted of special educators and children with similar developmental delays who gathered a few times a week to work together with social interaction and some language stimulation. Matt continued this support until he turned three and qualified for early intervention.

We also utilized the Easter Seals program, which services children with mixed disabilities in a group setting. It was quite obvious that Matt was making limited progress within this setting, but we still forged on. It was then that we researched and networked with other local families to find scientifically and research-based services to give Matt a fighting chance to overcome all the challenges that go along with autism. Matt participated in this Easter Seals program while waiting to move up on several waiting lists to receive intensive interventions from a more specialized program utilizing the principles of applied behavioral analysis (ABA), specifically for children with autism within a home setting. At that point, we networked with other families to find an agency that was able to staff a program for Matt and work on language, social and life skills within the home setting.

### **Please share some of the things Matty struggles with as a result of his autism.**

The biggest struggle Matt has is lack of language. He is non-verbal so he cannot fully express his desires and needs. He

**Matty W.**



can also not read, write or type on a computer. He is not able to understand the fun associated with any type of game and I am not sure if he understands what fun is. Physically, he has gastrointestinal issues and epilepsy, and also has a lot of trouble sleeping.

**Please share some of the things at which he excels.**

Matt is pretty good at doing puzzles. I wish there was more to highlight but honestly, I'd say his superpower is having the patience to deal with very rough and frustrating conditions. He can complete simple tasks like sorting, carrying, sweeping up - ones he does put to good use when he volunteers at the Greater Pittsburgh Community Food Bank - and he brings out the best in people. Those who work with him and get to spend time with him absolutely love him.

**What makes you most proud of your son?**

I am so very proud that Matt endures all of the challenges associated with his autism with such patience and good humor. Given that he cannot express his desires and is physically impacted by his conditions and medications, he is generally cooperative, happy and gentle.

**Matty W.**



**What advice would you give to other parents with a child/children on the spectrum?**

Dealing with autism can be a struggle - I can't sugarcoat it. It is hard but there is hope. The resources, therapies, medications, services, understanding, and knowledge today is significantly better than it was for us 25 years ago. If you educate yourself, network and advocate for your child, real and genuine progress is possible and may be likely.

## Please share five words that best describe your son.

Gentle. Patient. Inspiring. Sensory. Loving.

*The story shared above represents the experience, views and perspectives of the individual(s) highlighted. We aim to share stories across the spectrum and throughout the life span, but the information provided on our website is not a recommendation, referral or endorsement of any resource, therapeutic method, or service provider and does not replace the advice of medical, legal or educational professionals.*

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