

Please don't try to fix me; love me for who I am

We all remember the time and day when we were given the diagnosis: your child has autism. I can still see myself standing in a hallway, tears running down my face, holding a stack of brochures, with my 8-year-old daughter and my three-year-old son looking at me in shock.

Somewhere I remember the voice of the doctor saying, "I want you to come back in six months", while in my head all I could hear was, "why"?

On our walk to the car, my daughter told me she was sorry I was sad, and my, autistic son tried to push the tears back into my eyes. "Mommy don't cry, I will fix you mommy", he kept saying.

What followed for our family was a period of mourning, of letting go of dreams, of reassessing expectations and goals. I was both empowered and cursed with a lot of education and knowledge. I was trained as a medical biologist and had spent my entire working life until that point working as a researcher. I had heard leading experts in the field of neurobiology speak and could read the latest journal articles. None really filled me with much hope. There was and still is no known cause of autism spectrum disorders, there is no known treatment or therapy.

Many adults on the spectrum are not able to get or hold a job or live independently. There are also so many labels and misconceptions about people on the spectrum: they cannot sense or read emotions, they are not empathetic, they have odd behaviors, they just need more discipline, there will be some magical way to "fix" them, they will never make friends, tell you they love you or know really joy.

In the early days, I spent a lot of time reading and researching how to best support and help my son. The area we lived in at the time had few to no resources for families like ours. I did benefit from having decided when Matthew was born to home-school our daughter and the local group was active and supportive. I was very fortunate to make a friend of another mother who had a son who was on the spectrum too.



Matthew had a lot of sensory issues which meant that he would constantly need hugs, or he would pinch me. At the end of the day, I would be exhausted and could not stand anyone to touch me. I read about different therapies including Floortime, RDI, DIR, and the Listening program; therapies that could be tailored to Matthew's needs. We had an indoor swing, stability balls, and a mini-trampoline. I even built some of my own equipment; a larger ball bag, and weighted vests and pillow. Having everything integrated in our day, rather than having to go somewhere for a therapy session was an enormous help and Matthew began to be able to self-regulate, deal with some stresses, and become less sensitive.



When we moved to New Jersey four years ago for my husbands' work. I had homeschooled both Matthew and his sister Elizabeth for almost 14 years. The homeschool community we were part of was very supportive but we did not know anyone here in New Jersey. I needed to find a supportive community and a place that understood us.

Through some research, I found Celebrate the Children and the after-school program. After our first day at CTC, Matthew asked me, mommy, when can I go to school here? And after our second time, mommy, I want you to meet my friends. That day in the car I cried but not because I was hopeless and sad, but because I was happy and had a new perspective on everything that could be possible.

"Please don't try to fix me, love me for who I am," is the theme song of Celebrate the Children. Every aspect of the school has the ultimate goal of not trying to "fix" our children but to love them for who they are with all their unique gifts, talents, and abilities and to help them be all that they can be.

Matthew has been attending CTC for three years now and has never looked back. He has made friends become a leader among his fellow students, performed in the school musical, represented the school at a conference, and last year worked a job through the community-based instruction program. Matthew had a job at a local retailer (TJ Maxx) organizing shelves. He enjoyed his job, getting dressed in professional work attire, and having co-workers. Having a job, made him feel valued and responsible.

Sadly, like many of us, the COVID-19 pandemic has stopped this work and had radically changed our lives again. We have slotted back into homeschooling more easily than some but Matthew says he misses his friends, his teachers, and the staff at CTC. With Matthew, we made the difficult decision to remain home. One of Matthew's main concerns has been how to keep others safe from becoming sick.

We have come a long way from those first dark days of sadness and hopelessness. CTC, the students, staff, and support staff have been a big part of that. Although we face many challenges right now, I am hopeful for the future and for the future of the whole Celebrate the Children community, because we are not trying to "fix" our children, we are celebrating them in every aspect of their lives, we are loving them for who they are.



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Matthew and Elizabeth Sharp's mom and Greg Sharp's wife