

My name is Celena Sousluaga and I have two children with Autism: Emily, 9 years old and Daniela, 4 years old.

Looking into my past, I remember myself 6 years ago, walking with my little Emily, knocking door to door in the community, looking for help, because she was not able to say one word. Emily did not have a viable way to communicate with her environment. There were a million possible diagnoses and prognosis, but I didn't have an adequate doctor. I didn't have the knowledge that I have today. To make matters worse, I did not speak English so I was unable adequately and correctly express my concerns.

My life was falling apart as I began thinking my daughter had special needs. Her look was distant and displaced and she was unable to focus on her surroundings. I was worried about how she would be able to live on her own, once I was not here to help her. I was worried about her diagnosis and prognosis; I was worried about how I could transmit my thoughts to a doctor who cannot speak my own language.

Fortunately, I found someone to share my worries. I found the right program and the right pediatrician from the RHRC. This group of people provided me with an early intervention program, parenting classes and faith, because they acted as my family's voice inside of this community. They walked side by side with me, making this mountain easier to climb. As a team, my pediatrician, the ParentSmart program coordinator and my family educator attended my daughter's IEP meetings to advocate on her behalf and find a special program to meet her needs. I also want to express my appreciation and eternal gratitude to the extraordinary staff of Richmond Drive Elementary and its principal, Mr. Pat Maness, for also being part of this team of advocates. This is not a situation you encounter on a regular basis because most professionals limit their work according to their job description. When you truly love your job and your profession, you become passionate about what you are doing and how you are doing it. It transcends into the type of service you provide. That is the noblest part because, indeed, you are advocates for your profession.

Four years ago, I had my second daughter, Daniela. She also suffers from Autism Disorder. I did not know it could be genetic, but thanks to the early diagnosis and intervention from Dr. Edwards and ParentSmart, she is in the process of flourishing. Just like Emily, she is learning with more difficulties than other children. Through this new challenge, I have learned that, in this life, anything can happen but one must "never give up".

To have children with Autism means having your entire family with disabilities. Each day is a new start, a new battle and a new challenge. To have a good general concept of raising an autistic child means you would have to look at the challenges of one healthy child and multiply it by two, which translates for me that I have "four" children, or twice the challenges of a family with two kids. Do you know what Autism means? I will present you with a glimpse of my daily life.

I have to run between therapies, meet with professionals, advocate at school, deal with a meltdown in the middle of Wal-Mart, argue with friends who feel that we are parenting wrong, chase my second little child as she escapes down the block, watch my older daughter change clothes twenty times, before she finds the one outfit that feels comfortable. That is definitely not a parent's general concept of being successful. However, when you have children with special needs, you perfectly fit inside this

concept and are deemed successful because you have to be super human to take these challenges and stresses, and you have to multitask more than most parents. We don't have a choice in doing this differently because we are our children's voice, protectors, mentors, sources of love, and the only ones who truly know them. We are our children's link to the world, and with every day that passes, we have served that role with honor and passion.

At the end of the day, as I drag myself to bed, I smile because I made it through another day. Regardless of the challenges that were presented, how much I feel I accomplished or didn't complete, I made it through another day protecting my family, advocating for their needs, and scaffolding this chaotic world for my children. Sometimes I feel completely exhausted, leaving behind a million things still to do. However, if my family is safe, protected, and receiving my love, I have had a successful day!

Parenting special needs children takes fatigue to a higher level of exhaustion. I sometimes go seven consecutive days without sleep because my Daniela is not able to sleep, even with medication. I become physically and mentally tired from dealing with my daughter's issues and their environment; dealing with therapists, doctors and teachers; spending a lot of time researching new treatments, and advocating for them in the educational system.

Parents like me deal with depression because it hurts when I see my daughters struggling so hard to learn to do something that comes naturally to a typical kid, like interacting, talking or playing. It can be difficult at times to hear about the accomplishments of my friend's kids.

As special needs parents, we are scared about a new prognosis and diagnosis in the mental health area. We are scared about possibly not doing enough for them. What if we miss a treatment or a diagnosis and that window of optimal time and opportunity to treat has passed? We are scared about our finances. Yet, the most terrifying thought is wondering what will happen to my children if something were to happen to me.

As education opens up to us and we become aware of new horizons, we have to deal with the stigma from those who are around us. This is one of the aspects that empowers me to advocate about Autism. I have been challenged and pushed beyond my limits in raising my children and to try to educate my friends that Autism is NOT mental retardation. Autism is an impairment that prevents children from communicating with their environment. Through this education, I have grown tremendously as a person, and developed empathy for others that are in my situation. By devoting my life to raising my daughters, my dreams and my goals have been changed. I still have dreams and aspirations of my own as I would love to learn English one day, when my mind is less stressful.

I understand education makes a positive impact in the human ability to excel and it is the key to having a better future. Education about Autism allows me to educate my husband who walks this path with me, 24 hours per day, step by step, in order to make our daughter's lives more comfortable.

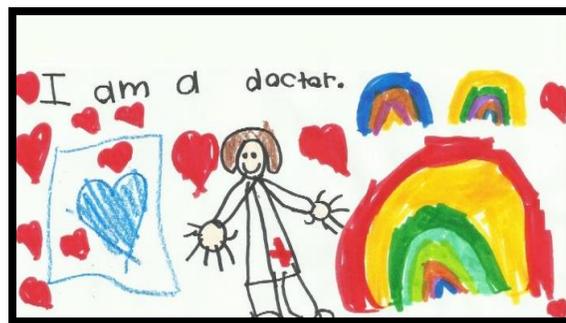
When special needs occur in a parent's life, you feel like everything is crumbling around you. It takes time to accept it, stand firm to face it, and then advocate for yourself and your children. The only thing that can help a parent walk through this process is to find the right support, and the right people. These

are people who, instead of judging your parenting, help you and give you the courage to embrace a new day and go on, moving forward. I was disabled due to my children's disabilities, but thanks to you who have supported programs like ParentSmart to exist, I have been empowered to be the voice of my children from now on. I was walking through all the stages of grief: shock, denial, anger, depression and finally acceptance. I came from being riddled with emotions to standing firm for advocacy. And here I am, standing in front of you all to invite you to walk with me in this new journey. The more mental health we promote the closer to a brighter future we are. Let's make a difference in our Rock Hill community; let's make this town the first one to stand on behalf of mental health, the first one to break the stigma and promote mental health.

You are the representatives of education and you make possible the education of our children, our teachers and parents in the community. Let's stand to educate health professionals and the public about mental health.

My journey started with my children because I am living this experience and culminating my advocacy for a better mental health system in our community. By being part of this education system, I have learned this is a team effort. I invite you to be part of this team and be the voice to promote and motivate better resources for mental health in our community. With respect to advocacy, my voice can reach your level and be heard, but your voice can reach the state level and be heard by a larger audience.

I am here to thank you and express how proud I feel to be part of the Rock Hill School District because I am one of your students. I am **ParentSmart**.



Picture drawn by Emily expressing her feelings towards the clinic doctor.

Emily stated she wanted to be a doctor.