

This is me.....and I make no apologies! A diagnosis, so what!

I'm writing this article while I'm listening to the song "This is Me" from the movie "The greatest showman". I have written this article over a hundred times in my mind but never felt the peace of mind to put in on paper. Not even thinking about sharing this with the outside world, a beautiful world but also a world where we need to fit into a perfect picture. A lot of pressures and expectations seem to rule this society, but what happens when you don't fit into this perfect picture? People will talk behind your back and will form an opinion of you, not always in a bad way but most often they seem to know exactly what you should do, without even knowing the story behind the person. The fear of what people think of me and our family was holding me back from writing this article and sharing it with the world. But moving to Miami from Amsterdam with my beautiful family I learned a lot about myself and other people, one of the things I learned is not to hold back on my goals in life because I fear the world outside. Despite this, I am still insecure about what people think, but I must let it go if I want this topic to be shared and to help other parents who might be in the same situation. As mentioned in the title please don't apologize and be proud of your children, they're unique and give color to this world!

Most of you know me by my Instagram "Mini and Me by Sharon" where I share our family adventures through my passion for photography. A real-life photo album and diary for me and my family where I share the highlights of our Miami adventure and anything which has to do with our family life. But Instagram isn't real life, as we have mentioned several times, but that's ok because every time I open my own account and scroll through my pictures it leaves a smile on my face to see how we celebrate life. Family motto: "Enjoy the small things in life". Moving to Miami wasn't always easy, and I can tell you we had a lot of ups and downs the first year, but nobody told me life would be easy, if you want to achieve something, you have to work for it. So we did, and we did it as a team, Team Shaki, when we look back we're super proud of ourselves and the boys, what doesn't kill us makes us stronger! But life is always full of surprises and when we thought the first year was a rollercoaster, we were wrong...

Living abroad means, you will most likely have to raise your children bi-lingual, in our case the boys learn Dutch at home and English at school. For Miami standards that is pretty normal because the majority of Miami is bi-lingual, English/Spanish. This means that a lot of the kids in the classrooms have to learn English in school because they learn Spanish at home. That means that the boys also hear a lot of Spanish, not an easy start if you still need to learn how to talk. So when our youngest son was still not talking at the age of two we were not surprised and certainly not worried. He was producing a lot of sounds and we figured he would be ok. After all, he was an early walker and they say when kids start walking early, they start talking later. After a visit from my parents where they had the pleasure of spending a lot of time together with the kids and we enjoyed a night away, they invited us for a lunch which turned out to be a serious conversation. I still remember the lunch, it was at Mignonette, a great hidden gem in

downtown Miami. It was a perfect lunch, with a lovely open conversation about our son and luckily over a glass of wine. During their stay with the boys they made a natural observation regarding my youngest son and noticed some small differences compared to our oldest growing up. This is where our journey started.

As a mom you want your child to be healthy, so a medical journey with your child, at any age, is always an emotional one. The main reason we started this journey was the lack of response to his name, so we started with a hearing test. When we got the results directly after the test and were told there was nothing wrong with his hearing, we started to worry a little bit more. From there to where we are today, we had many visits to the hospital with different practices. We got to learn the American health system in a hard way and in a short amount of time. What we already knew from the beginning of our journey, was that our son had a speech “delay” and that early intervention would be key for him to fill in this gap. It became pretty clear that he needed “Speech therapy” but most insurances only “cover” 20 sessions per year, leaving you to pay 50 dollar per session out of pocket and after those sessions, to pay the full price. Those few sessions wouldn’t make any difference for him, so the journey continued. After multiple conversations with his neurologist, we decided to do the ADOS (Autism Diagnostic Observation Schedule) test.

This is a semi-structured assessment of communication, social interaction, and play (or imaginative use of materials) for individuals suspected of having autism or other pervasive developmental disorders. Doctors look at the child's behavior and development to make a diagnosis. ASD can sometimes be detected at 18 months or younger. By age 2, a diagnosis by an experienced professional can be considered very reliable. However, many children do not receive a final diagnosis until much older. Diagnosing autism spectrum disorder (ASD) can be difficult, since there is no medical test, like a blood test, to diagnose the disorder. Doctors look at the child's behavior and development to make a diagnosis. Not all children with autism show all the signs. Many children who don't have autism show a few. That's why professional evaluation is crucial.

After our “final” conversation with the neurologist, she explained us that she wasn’t totally convinced if he was on the spectrum but that the ADOS test did show a development delay. To ensure he gets the right support through the American health system, he was diagnosed with ASD. I think it was a bit of a relief that we got the diagnosis after all these months and we could finally put words into action. The diagnosis gives you the opportunity to work with your child on Behavior, Speech and Occupational therapy. Those are the main trainings (this is how we prefer to call them) you need with a diagnosis of ASD. But the most important thing to help your child is to accept the diagnosis and not go into denial because early intervention is key to give them the life they deserve. However, it took us months of work to get our insurance in shape and to find the right fit for him and a good place for his trainings. Where we in The Netherlands have a fixed personal contribution for our health insurance of 385 Euro per year, the United States health insurance system deals with “out of pocket” payments and deductibles of thousands of dollars before anything is covered. Another big change in our life since we moved to Miami, but

we're blessed with the amount of support we got emotionally and financially from our family and friends.

January 28th 2019 was the day our son started his "new" life and I can't tell you in words how proud we are of him! Nothing but respect for our little baby boy who goes to a regular daycare (The Growing Place) in the morning until 1.30PM, where he is doing awesome just like any other kid in the class. The afternoons he spends his time at Crystal Academy for his one-on-one trainings. He loves both places and is always happy to go. Luckily for us and for him he doesn't need an afternoon nap anymore and by the time he comes home he is still full of energy. I can't tell you how blessed we are with all the people around us, who work with him day in and day out with so much love. We see him grow every day and even though we're not there yet, we already see so many changes and we believe in him from here to the moon. A diagnosis...so what! It gives us the opportunity to work with him and help him because he needs it now, and I know we're lucky because some of the professionals already tell us he might turn out to not be on the spectrum but we do need to work with him on his communication and developmental delays. The future will tell but for us he is the best in every single way!

Today it's almost 10 months since we started this journey and I finally found the time and the courage to share this article with you. This isn't only a special moment for me but it's also the very last day of World Autism Month #autismawarenessmonth. The reason for sharing my story out in the open is to tell all the parents out there not to apologize and to be proud and strong for your kids. We need each other and together we stand strong because at the end of the day our children will make this world unique!

If you have any questions for me or just want to reach out please do so, I'm happy to listen or just to be there for you.

"The greatest showman"

**I am who I'm meant to be, this is me
Look out 'cause here I come
And I'm marching on to the beat I drum
I'm not scared to be seen
I make no apologies, this is me**