

Abilities outweigh Disabilities

A look at my Journey.

1. Tell me, the viewers your why behind saying YES to The Collaborative Community Mission?

- a. JaHanna – I personally didn't even know this was happening until maybe a few short weeks after my job put on a fundraiser for We Rock The Spectrum Kids Gym – Buffalo. Once Jess mentioned it to me, I thought "Wow, that is great. So many families are going to benefit from this." Then about a week or so after we made our donation, I got a text from Jess asking me to be a part of this team. I turned to my husband, while calling my mom on FaceTime and said, "OMG Jess just asked me to be a part of her nonprofit journey." For about 20 seconds I was like, Can I do this? Do I have the time? Of course, I have time, I am going to make time to help other people. It is how I was raised, so there was no way I was walking away from this. I was honored to be asked. Jess is like family, and family supports family. We have stories to share, so I think these women have created a great foundation to do that. The mission and vision speak for themselves and truly embrace the things we want not only for our families and children, but for everyone else. Everyone deserves to know what services are out there for them.

2. How do you fit into the mission and vision The Collaborative Community Mission has created?

- a. JaHanna – For me, just wanting to help. When Roman was diagnosed, I knew nothing. I didn't know what was available to me, what he would need, just where to begin. People were coming at me from all different directions. I am so thankful for the support we had, not just from our families, but in Roman's entire therapy team and his EI Rep. It was a game changer. I am not much of a group person when it comes to sharing, like therapies, etc. I am not comfortable in that type of setting. So, it was refreshing and a relief to have such an amazing team from the start. Even now, with Jessica and the rest of these amazing women, the staff at Lakeview Children's World, it literally just leaves me speechless. I often ask myself, where would I be if I didn't have a strong foundation of people who were more than willing to help us? It literally takes a village. We have crossed paths with people who have turned into family. What a difference it makes to know you aren't alone, and that there are other families wondering and wanting the same things you do. Pulls at my heartstrings.

3. Speaking to some of your experiences you just described, can you talk about what it was like getting your child's diagnosis's?

- a. JaHanna – I mean plainly put, gut wrenching. My heart literally felt as if it fell to the floor and I was outside of my body. I had heard what the doctor said, but in between my weeping and trying to understand, I just couldn't put it together. I think, at least for me anyway, when you grow up and envision your life, you have an idea of what it is SUPPOSED to be like. No one, and nothing can ever prepare you for what it is, because it is always changing. At that very moment, Down Syndrome was not a part of my plan. It wasn't what I envisioned my child to be. To this day, I carry all the guilt in the world right now and I hope one day it will subside. There was a time when I couldn't even say the words Down Syndrome. I think if I hadn't heard, "I am so sorry," or, "Your son won't do

this/that,” that day in the hospital, I wouldn’t be carrying all this guilt. NOT one medical staff member in the hospital that day, aside from the amazing Doctor who delivered Roman, told me what my child was going to do, that his diagnosis isn’t who he is, that he would start school at a “typical” age, that he would show and have every emotion any “typical” child would have. It was just constant negativity. So, how could I not think anything but the worst? I cried for three months straight. Some days with my husband, and other days alone. I’d ask myself, what did I do? I think I was calling my mom every day and night, just sobbing. I am not sure I would have gotten through those first three months or his first three years without my mom. Our family’s support was amazing, but there is just something about a mother’s love. You know, when I met Roman’s two therapists, it was then that I knew my son was going to excel and EXCEED expectations. They were coming from the outside looking in. They pushed him, loved him as their own, and never let him settle. Much like we do. Is he delayed in some areas of development and growth? Yes, but aren’t we all? We are all learning, and that is what life is. It is an environment built of experiences that allows us to grow and develop through hard lessons and amazing experiences. Fast forward to today and I no longer cry tears of sadness for my son Roman. I cry tears of joy for all that he has accomplished and continues to accomplish. He has changed our entire world for the better. He is sweet, kind, stubborn, independent, loving, and curious. I think the women from the podcast, *The Luckyfew* said it best: “What breaks your heart drives your passion. See all children of all abilities for who they are. We are all created with a purpose and no one’s value should be based on the number of chromosomes they have, shift the narrative.” My son Roman, is HUMAN, a boy who just happens to have Down Syndrome.

4. When you look at families in your community who are struggling to find and receive the resources they need, what do you do, what do you say?

- a. JaHanna – Prior to jumping on board with this team, I used to just pray for those in need, and count my blessings. It is sad to see, but it is reality, right? Not everyone is provided the same opportunities, not everyone has the same support system. Everyone has their own narrative that has created the chapters in their lives. Some good, and unfortunately some bad. Now with this platform we have created, our potential is limitless. It is surreal. I am eager to start helping one person, one family, and one group with the services they need. Never in a million years did I think I would be doing anything of this caliber. It is an honor, I am grateful.

5. If you could give advice or say something to medical staff and their teams, what would it be?

- a. JaHanna – Step out of your medical jacket for whatever amount of time you are about to spend explaining or informing a family about the UNEXPECTED. You are human, too. I think you can still be empathetic and professional. Though, ethically, it may not be proper or professional to be empathetic when speaking of the unexpected, but I’d like to think there is no law that says it isn’t allowed. I am sure many medical professionals go home to a family foundation, whatever that may be, so I’d hope they would want their family and friends to be treated the way they treat others regularly. Lastly, stop listening with the intent to instantly respond. HEAR your patients. Their concerns are valid to them and should be to you. Remember why you started your practice in the first

place, and if for some reason you think you started it for the wrong reasons, now is the time for change. There is always room for change, better yet, growth.

6. What about your younger self, what would you tell her?

- b. JaHanna – Oh boy.....slow down, be kinder and more open! Amongst other things. I wasn't ever intentionally mean or a bully, but I didn't let people in. I didn't ever go out of my way to be overly kind to those who may not have been on the same track as me. I wish I would have. Now, I have a wonderful child whose track will be completely different than everyone else's, as it should be. I can only hope that people treat him with kindness, love, patience and respect. Becoming a mom has changed my outlook on so many things, being kinder and less rigid being just a few. I think you can still be kind, and not get walked all over. With all of that said, the path that I took has contributed to the women, mother, wife, daughter, and friend I am today. I do believe my journey; my chapters, are exactly how they are supposed to be. Everything allows for so much growth, if you look for the lesson in it. I pray every day that the parents my son sees in my husband and I, make him proud of us; that he knows our love is unwavering, and he will always have support and family no matter what. Love, love is a powerful thing. We all need more of it.

6. Lastly, what would you tell other women?

- a. JaHanna - To fight. Fight for yourself, your child, your family, what you believe in. Fight for everything that has ever meant anything to you. Never give up and throw some kindness in there. You don't know everyone's story, what they have gone through or are going through. I am a firm believer that everyone is fighting a battle we know nothing about. I think that is why every day I have grown more and more passionate about being a part of this journey with Jessica, Suzanne, Amy, and Katy. We are learning and growing together. I know we are a great example of what it looks like when women support women.

Final Word from JaHanna Kurtz:

This post took a lot of courage to write. There are many people, some even family who don't know this story. At first, I wasn't sure why I felt so compelled to tell my story, my families story, Roman's story but I thought, it is time. My son at 3 years old has taken away my feeling of shame, and failure. He reminds me every day the resilience of children. If anything, he gives me strength every day. Too friends and family of those who are fighting a battle, whose normal may not be your normal, know that differences are a beautiful thing. They set us up for a world that is ever changing. Differences remind us of how much we can learn from one another. Embrace it. Change the narrative.