

## An Orange Socks Story - Courtney and John: Autism Spectrum

Interview by: Gerald Nebeker, President of Orange Socks

It was a pleasure to go to the home of Courtney and John for an Orange Socks interview. They adopted Bella as a newborn and were excited new parents. Bella exhibited behaviors early on of someone on the autism spectrum and having a mood disorder, but these symptoms were only recognized later on when Courtney and John reflected back after Bella received these diagnoses at age nine. Bella is now 12 years old and has made great strides with proper medical treatment and behavioral interventions. I got to meet Bella, who is a delightful person and a blessing for everyone who knows her.

Gerald: Courtney and John, thank you so much for taking the time to meet with me.

Courtney: Thank you for having us.

Gerald: It's an honor. We are talking about your daughter, Bella, whom you adopted. Do you want to tell me a little bit about the adoption?

Courtney: Yes, the adoption took place at birth back in 2005, and it was kind of a whirlwind honestly. I had been through a series of miscarriages, several years' worth. In the spring of '05, after I was pregnant for the 5<sup>th</sup> time, I looked at John and said that, "If I miscarry again, we are going to adopt, my heart can't keep doing this." I knew with all of my heart that there is a baby who is supposed to be coming to our family. I did miscarry again, and we were building our first home at the time. We said that when we get into the home, we will go and start the adoption process. About two and a half weeks before we were supposed to close on that home, we got a call from a friend who said we should make this phone call right then, that there's a baby being born in California, and the baby needs to be placed, so make this call right now. We made the call and flew to Texas to meet the birth aunt who was facilitating the adoption, about three or four days later. Bella was born about 10 days after that in California and was in our home a couple of days after that.

Gerald: Wow.

Courtney: It was quite literally a miracle, even the process of getting her into our home. We had no home study even when we started the process.

Gerald: That's interesting. John, after a period of time, my assumption is that you started to realize maybe Bella might have a couple of issues.

John: She struggled as she got a little bit older. She was very fussy, and she never really interacted well with other kids. She just never had the ability to control her emotions, and it always showed. She was scratching, biting and pinching, and we were very young, and my take has always been that, "It's okay, she's okay." Courtney

was the one with the foresight to say that, “There is something going on here, this is not normal,” but we didn’t really have a clear understanding of what it was. The fact that she was adopted in a whirlwind meant we didn’t have even the knowledge to know what questions to ask the birth parents. There was a lot of information we found out later that helped us better understand what she was dealing with at that time.

Courtney: Because of the whirlwind of the adoption and because of our age, I was 23 years old when we adopted Bella, it’s not a very common story, but I think we felt so strongly about starting a family that none of that mattered. Age didn’t matter and circumstance did not matter because this baby was meant to be with us. John’s absolutely right in that everything came late for Bella, but we didn’t know it was late. She walked a little later, and she definitely spoke later as she was well into age three when she started speaking. I didn’t know that was different. John’s also right in that she acted out aggressively a lot in those toddler years. We thought it was because of communication and speech.

John: Frustration.

Courtney: Frustration based on communication. And for years and years and years, although we knew Bella had problems, we often thought we were trying to treat the symptoms through speech therapy and other things. Or trying to change our parenting style because it was us that she was hitting or whatever it was. It was through those toddler years for sure that we thought something was going on.

Gerald: So, when did you get a diagnosis?

Courtney: We treated the symptoms for years. There was never a diagnosis until two and a half years ago. When she was a little over nine.

Gerald: What caused you at that point to maybe seek a diagnosis or to seek some assistance?

Courtney: To be fair, she’s had assistance her whole life, but very much on the peripheral issues

Gerald: Okay.

Courtney: Like I said, she had speech therapy tutors for school. We were treating symptoms for a very long time, and a lot of it, honestly, is because of our own personal paradigms with the world. We have never been big fans of labels or diagnoses. “It’s fine, it will work itself out, if we just act this way, it will all be okay.” In many ways, I still really believe that, but at that same time, it really prevented us from getting the care and the diagnoses that she needed to move forward. In all reality, the impetus for that was when we moved and she got into a school situation that was not healthy for her. My daughter is a fighter, and she adapts really, really

well, and I think that's one of the reasons that it took us so long because she's incredibly...

John: ... adaptive.

Courtney: Yeah, she is.

John: She has the ability to see what's going on and try her best, and for years in school, she was able to fill that gap of what her ability was to what her peers' abilities were by adapting and in some ways, tricking us and helping us believe that she was able to do it by whatever her mechanism was.

Courtney: She has incredible tools that she utilizes to her benefit, and that's all we knew. So, we moved, and she got into a school situation that ended up being incredibly unhealthy for her to the point that her aggression and her anger hit a tipping point where it was no longer safe for her and no longer safe for us.

John: And her brothers.

Courtney: And her siblings, and we were at kind of our wits' end. We didn't know what to do. I happened to be at a conference for work, and I kind of just spilled my story and my feelings to a friend that I knew through work. She has asked if she had ever seen a psychiatrist, or if we had ever considered in-treatment patient care, and of course, my first reaction was, "Of course not, she doesn't need that, we are fine."

John: Before that, we had started seeing psychiatrists at the local hospital.

Courtney: Yes, that's true.

John: Insurance has never done a good job of covering those visits, and they were very expensive. Then we struggled to find a psychiatrist that we held onto for more than three months, because they were either on rotation or they got transferred to a different division. I think over the course of a year, we saw three different psychiatrists, so we were never able to dive deep with who Bella is and what was going on.

Courtney: There was very little continuity of care, and so quite literally, that conversation took place, and Bella was in a place where we were having two- to three-hour major anger, aggressive meltdowns every single day. We had just kind of held on, and we thought that we'd figure it out and get through it. After that conversation, John picked me up from that conference, and on the way home, Bella was exhibiting incredibly unsafe behavior, things that make me emotional when thinking about, because it's so scary. She was talking about a lot of self-harm, and I said, "John, I think we need to call the University Hospital and see if there is any sort of help we can get." It didn't even occur to me that such help was there, because I didn't have a diagnosis, and I didn't have a doctor consistently helping me.

John: Who knew her.

Courtney: Who knew her enough to be able to say that we need this. Bella does not have the sort of mental illness that you can just see, she is incredibly adaptive. You don't know that there is a lot of angst and a lot of heartache going on. We called the University Hospital and told them what was going on. They immediately admitted her for a week under the circumstances that she was not safe for herself or for others. We are talking about a nine-year-old little girl who was talking about hurting herself and talking about killing herself. I knew it wasn't normal, but I also didn't know what to do, so thank goodness for that friend who provided that lifeline and validated for me that there were solutions and that this was okay to talk about, and so that really was an incredible turning point for us.

Gerald: And you got a diagnosis?

John: We started meeting with three or four psychiatrists, and then doctors, and all of a sudden, this team emerged that said, "We need to do this test, we need to do this test and we need to do this test," and it gave us so much organization to the chaos in our life at that time. Through that process, we came up with the diagnosis, which was a dual diagnosis of autism on the spectrum and then a mood disorder. Autism in girls looks very different than it does in boys. I think a lot of us have learned from modern day culture what autistic boys look like, I don't think it's very common what autism in girls looks like. We didn't even have that general concept of what autism in girls looks like, much less with the mood disorder. We learned some other things about her IQ and memory, and other things based on her genetics and where she came from that gave us some more clarity on why she was struggling the way she was in school, and not being able to remember things, and not having the ability to do what she wanted to do, which was causing frustration which, with her mood disorder and the way her brain was wired, caused her to react and do certain things.

Gerald: Now, I know you didn't like labels, but did you find some measure of relief or something in actually getting a diagnosis?

Courtney: Absolutely. Like John said, it brought out a team and a plan, it gave us tools to move forward. I felt like for several years we were stuck, that we didn't know how to get out of this kind of loop we were in of behavior. It wasn't without effort, and it wasn't like she wasn't seeing doctors, because she was. We saw psychologists for years, and quite frankly, things were misdiagnosed again and again. About two years prior to this whole event, we were told she had an attachment disorder because she was adopted, because some of those same behaviors looked very similar, but that wasn't right, and that's not what was going on. We were going down that path, but finally, through this honestly traumatic event of having to put your child in a psychiatric unit just out of the sheer need for them to get help, all of the pieces fell into place. It was like letting go of all of my own

personal expectations and preconceived notions that allowed us to get her the help and put us on the path of being so much more healthy today than we were then.

Gerald: Let's talk about today. She's 12?

Courtney: She's 12.

Gerald: So, it has been three years since that life-changing event of receiving the diagnosis. What's different now? What has happened over the last three years?

John: Well, the next step after that, we realized that things needed to change in her schooling environment and in her home environment. When leaving the psychiatric ward, they have this transition unit where they help the child and help the parents adapt back to a normal environment. That team of people was kind of life-changing. They loved Bella, and Bella loved them, and she grew to be comfortable with who she was. She learned some coping techniques that really changed everything. From there, she went back to mainstream school, and we realized very quickly that mainstream school was not the right place for her. It took another couple of months of going to the school district to petition to have her go to what's called a self-contained class, where she is in a smaller group of children, 8-12 kids, with three to four teachers who know how to deal with children with special needs and disabilities. That was the next transition of life that has made all the difference in the world. It went from kicking and screaming to go to school, to her now waking up half an hour early this morning, getting dressed by herself, and combing her own hair because she wants to be ready for school.

Gerald: That's great.

John: She wants to be at school because her friends are there. She is loved and accepted. That transition from hell on earth, where we were just dealing and surviving, to some of the most traumatic experiences of sending our daughter to a psychiatric unit, to then learning and going through the transition of a self-contained class, has been honestly a huge life shift for us. It has provided so much more peace at home. Her brothers are in a safer place, and our family is in a safer place, it has been a huge transition for us.

Courtney: And I would say not only safety is a huge piece, because we are very familiar with what aggression and anger can look like and feel like in a home, but also thriving.

John: It has gone from survival to thriving.

Courtney: Yeah, seeing her and being able to reframe our own minds to see her for herself and the beautiful young woman she is turning into, and being able to appreciate that although her life might look different than I expected, there is still so much beauty and so many wonderful things. We had her entire class over for her

birthday party a few weeks ago, and it was one of those moments as a mom where I had gone from where I didn't know if she'd ever have a friend, to seeing her interact and laugh and play and dance, and it was just not only incredibly therapeutic, but also so much joy.

Gerald: I wanted to ask a question, tell me about the impact that she has had on your extended family and her siblings.

Courtney: I'll speak to the extended family, and John can speak to the brothers. One of Bella's gifts and talents, because I believe everyone has gifts and talents, is that people love her. You can't help but just love her if you know her. The amount of love and understanding and increased empathy from everyone in our families is phenomenal. The opening of world views and mindsets based on this one individual child is pretty phenomenal. I think of the change that she's created in John and me, but then I think about the change that she's created in my mother, and the opening of love and understanding that has occurred, and I think that is just a piece of her manifesting out into all of us. She's loved wherever she goes, really, to know Bella is to love her.

John: The hard part is when people don't know her because her disabilities aren't visual, they are more mental. Sometimes you get an odd look in a store because she is having a hard time, and someone just can't look at her and see that she has missing legs, or maybe Down syndrome. It's not as visual, just different, so that's a challenge, but our family who has embraced that has been nothing but loving. And her brothers, a nine- and almost six-year-old take on, in some ways, the caretaker role. They know when she is having a hard day as soon as they walk downstairs. It has been amazing. Even since our youngest was three, he would say that, "Bella's having a hard day, so I better go into a different room." They've learned to adapt, and they've also learned to be her protectors and to show her unconditional love. That has been amazing, to see our boys develop empathy for her.

Gerald: That's great, what a progression has happened over the past 12 years. I find myself wondering, because some people want to adopt, and some people after they adopt find out that the child that they adopted has some challenges, if I were contemplating adoption, but I had some concerns about what I was going to end up with in a child, what advice would you give me?

John: I would start off by saying that I always find it interesting that people think they get to choose how their child is going to turn out if they adopt. I think there is a certain amount of uncertainty when you adopt, but then there is a certain amount of uncertainty when you have a biological child. We have two adopted children and one biological child, and you don't know what you're going to get either way. There is an aura of "I can choose," or there is this false perception that you get to choose how your child develops in all the different things, but that's not the way. Each child is unique, and you won't get to decide. You get to decide one thing, whether you love

and support that child or not, and that's really the only choice you have in raising a child, and that's the most important choice also.

Gerald: Courtney, there have been good times and there have been bad times, there have been scary times and then things are better. You've known Bella now for 12 years, was it worth it?

Courtney: The interesting part is that it's through some of our biggest struggles and unexpected moments that the most beautiful parts of our lives arise. My life is completely different than I thought it was going to be when we adopted that child 12 years ago, but it's so much better. I have had to change things, and yes, my expectations are different and our schedules are different. We have a lot of support and outside help, but those are all beautiful things, because, ultimately, I have her.

John: I think it was interesting when the diagnosis first happened and we came to the full realization of who she is and what she's going to struggle with, we both went through a mourning process. That was something we had to do individually, and at different times, we were in mourning for the life that we thought we were going to have, that we had already preplanned for, and adjusting to the life we had and then choosing to make the best of that life was a big paradigm shift for both of us, to come to that full realization and to love where we are at now. We have a beautiful life, and we have a beautiful child. She has asked some amazing questions. She asked me two days ago, "Daddy, what does my future look like for me?" It was hard, because this is something that Courtney and I talk a lot about. What is her future going to look like? How could we do what we can now to provide the best future for her? For her to ask that question, to have the mental capacity to ask that question, was a beautiful moment for me. "Bella, I have this vision for you that it's going to be beautiful, and you're going to have a great life." I'm not saying that to her because I'm just feeding her lines, I believe that because I have accepted who she is. She is beautiful, and even though it's not who we had thought she was going to be twelve years ago, six years ago or three years ago, she is a beautiful person, and accepting that wholly has been great for us.

Courtney: It really has. I don't think either of us are under the assumption that life isn't still going to be hard, and there still won't be difficult times and things that we won't know how to do. In fact, we are coming into the teenage years, which I know are difficult with any child, but we have additional difficulties with Bella's challenges. I know we can do it, and I know she can do it. I love what you said about the vision, and that's one thing that we've said to each other is that we will have a vision for her life, and we will hold it dear until she can take it on for herself. We'll nourish it and hold it, and we'll set it up until she can in whatever capacity that is, take it for herself and on her own.

Gerald: Great, that's super. Any final thoughts?

Courtney: It's our pleasure. I don't know how else to say it, it's our pleasure to get to be her parents. We didn't choose it in any way, but we get to be a part of her life and see the impact that she is going to have on the world, and hopefully facilitate it a little. It's just our pleasure to get to experience it with her.

Gerald: Great, well John and Courtney, you guys are awesome. Thank you so much for taking the time to meet with me to share your story. I really appreciate it, and I'm sure many people will enjoy listening to it.

John: Thanks, Gerald.

Courtney: Thank you.