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Actually, Looks Are Everything

By Christine Spencer-Hubbard

Please don't be fooled by the title of this article. Don't get me wrong, fashion is fabulous, but these looks come from a much deeper level. The looks that come from misunderstanding, uneducated and yes, unfortunately sometimes plain ole' mean people. I am referring to the looks from people when you have a special needs child. On the other hand, the "deeper level" of looks can also mean words that are unspoken. Especially when your child needs to feel reassured or understood and need compassion.

Last year our family traveled to Nebraska for a family reunion. Nebraska is quite beautiful. We stayed at Fort Robinson State Park. Our family loves activities and trying new adventures. It was a very hot day when my husband, children (Finn, Trace and Madison), and I decided to go horseback riding, one of the wonderful amenities the state park offers. We met a guide and he went through all the rules and assigned us horses. There were many other families attending the same trail ride. Finn was 8 years old at the time and he is on the autism spectrum and Trace was 6 years old and has Down syndrome. I wasn't worried about Finn as much as I was about Trace and how he might handle this new experience. Trace was still so little, and a mound of concerns ran through my mind but, he was so excited, I had to entertain the idea. My family had been separated from one another to accommodate the horses in a specific order. Once we all were saddled on the horses, they formed a line behand the guide. Madison (my beautiful daughter) was last, then me, then the line skipped a few people who we didn't know, then Finn and Trace. My husband was a few people ahead of them. A piece of advice, never go horseback riding wearing yoga pants! Back to the story, Trace started to let go of the reigns and moving around. My heart started beating faster and I thought ok, here we go. Thankful, the guide was very patient and kind. He nicely told Trace to hold the reigns and sit still and rode next to him for a while. I was looking ahead and all I could see was the back of Finn's head. I thought I heard him whimpering but, I wasn't sure. I was expecting him to turn around to look at me but, he didn't. I was trying to enjoy the gorgeous scenery that mother nature so gracefully gave us but, all I could do was concentrate on that whimper. I couldn't take it anymore. I asked the guide to come over to me and told him I was sorry for stopping the ride but, I must make sure my son was doing ok. I called out Finn's name and asked him if he was alright. Finn would not turn around and look at me. I finally demanded him to look and me. His eyes were red from crying and he said he was scared. Mind you, I wasn't worried about Finn. He was 8 and almost 5 feet tall and the horse he was on was maybe 6 feet tall so, I thought he felt safe enough. My heart just melted. Finn tried so hard to stay strong but, his anxiety got the best of him. I looked at Finn and said, "Honey, I understand and it's going to be fine".

Finn and I looked at each other the rest of the trail ride. It took me some time to realize that Finn wasn't scared of the horse, he feared not being in control and of the unknown. Finn wasn't familiar with horseback riding and didn't know what to expect from the trail ride. Needless to say, Finn and I both missed out on the enjoyment of the experience but, it honestly didn't matter, as long as Finn was ok. The look of compassion and sympathy from his mom helped him finish the ride.



I remember a few years ago I attended a conference about many different sides to Autism. Amy Matthews, a Psychology Professor at Grand Valley State University, not to mention a brilliant woman, was a guest speaker. Mrs. Matthews had mentioned a story about an autistic boy who would cry every time his mother would take him to the library. As soon as the mother would walk with her son to the library doors he cried and had an outburst. Mrs. Matthews offered a thoughtful reasoning to the room full of attentive personnel. Maybe the boy acted this way because the doors opened differently at the library. That simple reason made me more aware of the struggle of my children in certain aspects and other special need children.

I have been given looks of sympathy before because Trace has Down Syndrome. I actually have sympathy for them. They are missing out on the enjoyment I have raising him. My boys are an exception to the world of special needs. They are very strong and have overcome many obstacles thus far and continue to do so. I couldn't be prouder of them and I am so very blessed to have them in my life.

All my boys want is to feel understood, validated, and loved. They do not want sympathy from strangers or any handouts. They need extra time to grow and learn. They need to know it's ok to be themselves and still be accepted by others.

The looks I sometimes get from people, whether it be sympathy or annoyance, dose not bother me. I am confident raising my children and understand their struggles through this unpredicted life. I want people to know and be aware of the looks they give to others and the effect it could have on a parent or a child. Please don't judge a child screaming in the store or not listening to their parents. You think you know but, you have no idea. Looks, can actually mean everything.

Speaker Series and free events

April 10, 2019: Anxiety and Autism

Wednesday

6:30 - 8:30 PM

1703 Despelder St Grand Haven Michigan

Dr. Kaarin Anderson – Ryan will lead an interactive seminar. This presentation will provide an overview of anxiety, including basic features as well as symptoms of anxiety disorders. We will discuss the prevalence anxiety in autism spectrum disorders. Tools and strategies for managing anxiety will be presented. This is a **free event** registration is required. Email: contact@asws.org with your name and phone number.

Light refreshments will be served.

Have a Heart for Kids

April 13, 2019

Saturday

10 AM - 12 PM

1015 S. Beacon Blvd, Grand Haven

616.847.5293 GENERATIONCARE.ORG

Learn about resources in the community. Enjoy games, outdoor activities, therapy animals service provider meet and greet, adaptive equipment representatives, respite and support group information

Superhero Autism Activity Day

April 13, 2019

10:00 AM - 1:00 PM

Presented by Centria Autism

Three Mile Project

3053 Walkent Dr. NW, Grand Rapids

Join us for a day of FREE family fun at the 3 Mile Project on Saturday, April 13 from 10am-1pm! Whether you're getting your pictures taken with your favorite superheroes, running around obstacle courses with friends, jumping on the bounce house, getting your face painted by a professional, or getting creative with an arts & craft project, you and your family will have a great time! Space is limited so register early. https://www.eventbrite.com/e/superhero-autism-activity-day-grand-rapids-mi-presented-by-centria-autism-tickets-55429281473

2019 Blue Bridge Walk for Autism and Sensory Friendly Museum Night

April 25, 2019

Event starts at 4 PM, walk starts at 5PM

Our Bridge Walk for Autism is more than an event for the autism community. It's a rally for inclusiveness—for community members, businesses, and local leaders alike. In celebration of Autism Awareness Month, Hope Network and the <u>Grand Rapids Public Museum</u> are also partnering to host a sensory-friendly night FREE for children with Autism and their families.

This special Grand Rapids Public Museum event will include free Museum admission where they will adapt the sounds, lighting, and activities within their current exhibits to create a low-sensory experience for children with Autism.

April 28, 2019: Sensory Friendly Performance Junie B. Jones

Wharton Center Presents

1:30 PM

750 E Shaw Ln, East Lansing

Hurray! Hurray! Junie B. Jones is graduating from kindergarten and ready for first grade at last! But getting use to new friends, a new teacher, and new glasses is challenging, even for the irrepressible Junie B. Follow her adventures as she adapts to first grade, dreams of being the boss of lunch, and creates a kickball half-time show. Junie B. ALWAYS writes everything down in her "top secret personal beeswax" journal, which give us the inside peek into her world. Spark your child's interest in reading with this musical based on stories from the popular books written by Barbara Parks.

In collaboration with the Wharton Center, ASWS is giving free tickets to this event. Simply send a request for tickets to contact@asws.org with the number of tickets needed, name and address. Tickets will be mailed to you before the production.

APRIL 30, 2019: Getting and Keeping the First Job

Tuesday

6:30PM - 8:30PM

Sign-in opens at 6:00PM Light dinner provided.

BLESSED SACRAMENT CATHOLIC CHURCH

110 N. Cedar Street, Allegan 49010

This workshop will look at important considerations for youth with disability preparing to get and keep their first job. • Straight talk about employment • What you need to know about employment • Accommodations, disclosure, and interviewing • The employer's perspective • Self-employment • Closing thoughts, questions, and evaluations

RSVP with Bethann Robins by April 23, 2019 (269) 364-6317 or bethann@michiganallianceforfamilies.org Register online www.michiganallianceforfamilies.org/rsvp

From a Mother's Heart

When I think about writing an article on Autism my mind does one of two things. It immediately responds by drawing a blank and refuses to think of even one word. I repeat, not one word. Or, my mind will react with rapid fire. Alarms are ringing and shouting "write about acceptance ... no, write about struggle ... wait no, write about unwavering love".

I sit.

I stare into space and for the life of me I cannot find the ability to muster up a single topic. Forget compiling an entire article based on one and stringing words together to form some sort of rhythmic pattern. This process led to the epiphany that this is exactly what Autism is like. Yesterday I had the privilege of attending a field trip with my son. We'll call him B. B has been diagnosed with ASD (Autism Spectrum Disorder) since he was 18 months old. We are what some like to call the "lucky ones". When ASD is diagnosed early, interventions can start that much sooner. We advocated for B and with help we found answers. Sorry. Sometimes I like to get off track ... back to the field trip. As mentioned, my mind is rapid

fire or blank stares. B's field trip was to the local bowling alley. Let me tell you, my son LOVES bowling. He begged for this field trip and his precious teacher made it happen. B attends a typical elementary school with a not so typical ASD classroom. I say that only because not enough schools have a class for children like B. Out of the entire service unit we're in, there is one class. The service unit consists of four school districts. B's classroom can accommodate seven children. According to the CDC in 2018 1 in 59 children are diagnosed with ASD. Did I mention our district has ONE classroom for four entire school districts? The demand is there. The need is there. The help however, is not. Apologies. Back to bowling. I met the bus at the bowling alley and greeted B as the bus door swung open. He was ecstatic. He had been counting down the days until the field trip for the last three days. His arrival was the equivalent of Neil Armstrong stepping onto the moon. It was monumental. I'll leave out the part where we exchanged his shoes for bowling shoes, picked out the perfect ball to hurl down the lane and the fact that B was asking for Doritos before he even bowled once. This is the first time I have been with B's entire class. He has only been in this class for about four months. Minus snow days, breaks and holidays it's actually been about three months or less. His previous elementary was no longer capable of meeting B's unique needs as a child with ASD. Have I mentioned the 2018 CDC facts? The comparison to the lack of adequate education for ASD children in each and every one of our school buildings? Scrolling back, I can see I have. Back to bowling. All seven children attended the field trip. As a parent of an ASD child I enjoyed every single minute of the trip. One child wanted to run down the alley lane every time he bowled. He is fascinated with anything mechanical and he wanted to see how the pin setter machine was working. Another child was talking on his ipad device "more candy". The teacher would hand him another skittle or two in hopes of holding him over until it was his turn to bowl again. One little girl sitting across from me was so excited that she kept shouting things over and over. I smiled at her. She didn't smile back. The oldest boy was quiet. He would bowl and immediately turn to walk back up the stairs to wait quietly. There were a few times that one or more of the children would be on the floor crawling and sometimes visibly upset. Another time a child was attempting to push over a couple of chairs to open the emergency exit.

Autism is isn't one topic. It isn't one behavior or one concern. It can't be described by an individual thought or a single article. It is a beautiful combination of countless individual traits, behaviors and patterns. Autism is 1 in 59. Autism is blank stares. It is rapid fire.

Save the Date

May 18, 2019 Annual Spring Fling Banquet and Celebration

It's time to nominate the everyday heroes in our children's life. Send nomination letter with why you're nominating this person for a You Make a Difference award and their contact information to contact@asws.org

August 10, 2019 Autism Awareness Walk

Grand River Park

New Resources

Caring.com is a leading senior care resource for family caregivers seeking information and support as they care for aging parents, spouses and other loved ones. They have been featured by AARP, The Administration for Community Living, The National Legal Resource Center, and Forbes, as well as referenced by many governmental agencies and organizations across the Internet.

<u>FreeGrantsForWomen</u>, a website that helps low income women with finding grants and financial assistance programs. These grants help families with education, rent, housing, utility bills, mortgage, and medical bills. http://freegrantsforwomen.org/

Message from the Board,

As we move into Autism Awareness Month we would like to announce our updated website. Working with Reagan Marketing this winter we have a new, fresh look, streamlined online services all the while keeping the website's autism information available to those seeking information and resources. If you haven't had a chance to see it we would encourage you to give it a try www.asws.org.

Looking over upcoming events you will see many opportunities to participate in activities throughout West Michigan. You'll notice there will not be a Puzzle Run this year. We are working with a company to certify a half marathon to the run and will relaunch the run in 2020 as the Autism Support West Shore Puzzle Run — featuring certified half marathon, 10k and 5k runs. This is a development year and we are very excited to bring more options to our runners. Our Autism Awareness Walk will take place on August 10, 2019 at Grand River Park. Ottawa County Park Service is co-sponsoring our walk. Grand River Park is the park ASWS has adopted for the Sensory Trail. This year's walk will feature a 1 mile walk for families, friends and supporters of individuals on the Autism Spectrum. Join us after the walk for a cookout lunch after the walk. (see attached flier)

April is also the time of year ASWS takes nominations from members for the You Make a Difference and Educator of the Year awards. Please send nominations to contact@asws.org by May 1, 2019 with a short nomination letter and the nominated person's contact information. While we appreciate all nominations a selection committee carefully chooses the award recipients. Our annual Spring Fling Awards Banquet will be held on May 18, 2019 at Grand Valley State University's Alumni House. Tickets will go on sale May 1, 2019.

Happy Spring,

Linda Elenbaas and the ASWS board