

# Autism Support of West Shore

*A place where everyone fits*



March 2020

Volume 2 / Issue 3

## Giving In

Karrie Hullings

It has begun. The process. The thinking and organizing of ideas. It's simple, just write some words down. Form some bullet pointed facts or ideas. Be sure to make them interesting and then string them together to form some cohesion. For someone like me who loves to express herself through pen and paper or keyboard and screen this should come effortlessly. Maybe even what some would call easy with a natural flow. But somehow this time is different. I'm no longer a student working on topic pieces about things such as Evolution or writing a book review about Of Mice and Men. This isn't a silly journal entry about my teenage years and who my next crush is and why. This is different. This is a blank page. No set topic to write about, it is my choice. It's left up to my discretion, I get to choose. Things are not the same as they were back then. They are different now. It's 2020 and I am an Autism mom now. Nothing is as easy as it once seemed. Things don't seem to follow the simple rules that my English teachers and professors drilled into me for the first half of my life. This is my reality now. Forming brilliant ideas and making cohesive sentences seems like a thing of the past. Making sense of the thoughts in my head when nothing around me makes sense is as difficult as it sounds. Next to impossible.

I have attempted to brainstorm ideas for an article to turn in several times over the last few weeks. It was unsuccessful. I have sat down to a keyboard and screen more than once. Sitting and thinking that by some magic in the universe words would just pour out and make sense. Again, to no success. By now in this process I would usually have an organized outline, some rough sentence drafts and an epic closing to wrap up everything that I have described. Not this time. This time I had nothing. I have been stuck in empty thoughts for days and days with no avail. Until today.

Today was different. I had just gotten my son off of the bus and was driving to pick up my other children from their schools. Again, I was trying to brainstorm ideas. However, every thought trail I was on was halted by my son trying to get my attention. I say "attention" but sometimes it's hard to decipher if he

actually wants my attention or is just trying to irritate me and push my buttons. Afterall, he is almost 12 and has become quite good at both. I should say, this is my son with Autism. We make this drive together every day after his bus drops him off. We head from Twin Lake to Fruitport where my other children attend school. As we were driving, I talked to him about his day with not much reply. Then it hit me. This. This is my life now. There is nothing organized and formal about this. This is what counts and this is what matters. Finding the words in the quiet or the chaos.



I park at the school and pulled out the notes app on my phone. I was PUMPED that I have decided to write an informal article based on our truth. I say to myself “just write about why it’s so hard” that’s the truth. That’s relatable. My fingers start typing. One sentence done and then another. It’s working! I feel like I am getting somewhere. As I am on a roll in my dreamland universe writing, I am abruptly shaken by my son grabbing my shoulder. Then he just stares at me. He does this often to get our attention so I say “no touch please” as I get back to my writing. I shake it off and begin again. Another couple of sentences down and my son starts licking his hands and rubbing his face. He then proceeds to grab my shoulder again. “Ah”! He’s looking for a reaction or attention and at this time I’m not sure which it is. I give in. I stop writing again and I tend to him. Once he’s settled and seemingly calm, I begin again. Words are coming. Sentences are forming and all of these interruptions are exactly what I am writing about. This is a lot easier now. This is honest. This isn't a research article on vaccines that’s been done a thousand times or a cute little article on the importance of self care. This is a mess. This is real! In true fashion the epiphany bubble is burst by my son yelling “McDonalds”! Demanding more attention, more redirection and I must give in. No thoughts can be formed while I tend to the demands of my child. And there are always demands. Even when he is not here, there are demands that take up the entire capacity of my brain’s free space. Some days there is room and others there is not. Some phases of our life allow more than others but, in this phase, today, this month even, it isn't possible. So, it will be ok. I will stop what I am doing and I will give in.

In the midst of this chaotic life and what seems to be a hopeless task, I have found the space to choose realness. The raw. The unfiltered. The outlineless. Stringing along sentences to show the truth in our journey. Writing an article all about nothing and everything at the same time. Our truth is that sometimes there is no space for anything other than Autism. I surrender. I give in to the interruptions and the important demands of my life.



## Our Concert



On **September 12, 2020**, a group of West Michigan musicians will be hosting an open-air concert at Lakeshore Middle School in Grand Haven. Our Concert is the creation of local musician, Dave Palmer. The premise of Our Concert is to include and embrace the greater West Michigan community. All individuals and families with typical and unique children are welcome to come and enjoy this amazing event. Not only will various bands play throughout the afternoon,

attendees will have the opportunity to participate in raffle prizes. The entry ticket will be your entry and a raffle ticket for \$5,000. Tickets will soon be on sale for this event. Tickets are \$10.00 and ALL tickets sales goes directly to ASWS. We are looking for individuals who would be willing to sell tickets for ASWS (great volunteer opportunity for scholarship recipients). Tickets will be on sale at [www.asws.org](http://www.asws.org). If you're interested in ticket sales contact Linda at [contact@asws.org](mailto:contact@asws.org).

## Communication in Special Education Meetings/IEP's

March 2, 2020

Herrick District Library

300 S River, Holland

Communicating in tense or emotional special education meetings can be difficult. The Office of Special Education understands this and provides no cost services to help parents and schools communicate about planning for students with disabilities. Special Education Mediation Services (SEMS) is a grant funded program providing mediation, meeting facilitation and communication workshops throughout the state. Learn how these services can help you enhance your support for students with disabilities. Presented by Cindy Van Neste, Outreach Representative, Special Education Mediation Services. Register for this free event at [www.asws.org](http://www.asws.org) under events.

### Sensory Friendly Performances at Wharton Center

Looking for a fun activity? Look no further than these free tickets to one of three sensory friendly performance at MSU's Wharton Center. Tickets are limited so get yours soon [www.asws.org](http://www.asws.org) Parking ramp fee (\$10) is not included.

At Sensory-Friendly Performances, accommodations will include:

- Lower sound and light levels; all strobe light effects removed.
- House lights on at a low level throughout the performance.
- Audience members are welcome to stand, move around, and enter and leave the theatre as needed.
- An Activities Area with crafts and activities for engagement.
- Designated quiet and calm spaces.
- Autism specialists and trained volunteers on hand.
- Sensory supports available (fidgets, earplugs).
- A Social Narrative that portrays the theatre-going experience with pictures and text.
- A Character Guide with pictures identifying each character in the show.
- Audience members are welcome to bring their own manipulatives, seat cushions, comfort objects, headphones, electronics, special snacks, and other support items to the show.

**March 15, 2020**

**1:30**

**Dog Man the Musical (3 tickets remaining you must contact [info@asws.org](mailto:info@asws.org) for tickets)**

A hilarious new musical based on *The New York Times* #1 bestselling series from Dav Pilkey featuring the crime-biting canine who is part dog, part man and ALL HERO! He's ready to take on Petey the Cat, the felonious feline who's always hacking up harebrained schemes. Songs for the show by Kevin Del Aguila, a New York Outer Critics Circle Award nominee for *Altar Boyz*, and Brad Alexander, an Emmy winner for *Peg + Cat*

**Recommended for ages 6-11.**

**April 26, 2020**

**1:30**

**Miss Nelson Has a Field Day (7 tickets remaining tickets available at [www.asws.org](http://www.asws.org) events)**

This fun-filled musical, featuring the Dallas Children's Theatre, takes us to Horace B. Smedley School where the Smedley Tornados have never won a football game. In fact, they have never even scored a single point! With such a poor record and a team that is out of control, kind-hearted Miss Nelson comes to the rescue when she enlists the help of her alter ego, the ill-tempered Miss Viola Swamp, to coach the team and whip them into shape.

**Recommended for ages 5-11.**

# Save the Date

## Michigan Council for Exceptional Children

**March 4 – 6, 2020**

80th Annual Michigan CEC Conference

Amway Grand Plaza | Grand Rapids, Michigan

Register by February 12, 2020 for discounted rates

<https://www.cvent.com/events/80th-annual-michigan-council-for-exceptional-children-conference/registration-78c3ca29c9a443c78d00496edd24eb3c.aspx?fqp=true>

## Meet and Greet Northside

**March 17, 2020**

6:30 – 8:30pm

Mancinos

13040 US-31, Grand Haven

Join us for a time of relaxed conversation. Children are welcome but babysitting is not provided. Dinner or refreshments are available to purchase. All are welcome.

## Access Expo

**March 18, 2020**

4-6 pm

Grand Haven Community Center

It can be frustrating to try and find helpful resources for visible and hidden disabilities. Searching for the right information and support can leave you feeling lost and overwhelmed. Join us for the third annual AccessExpo, where you can access the local resources you need to participate, contribute, and belong to an inclusive community.

• Job Opportunities • Disability Information • Local Experts • Access Information

## Sensory Friendly Night at RebounderZ

**April 14, 2020**

6:00 – 8:00pm

Cottonwood Dr, Jenison

At Rebounderz Grand Rapids, we realize during normal operating hours, our facility can be overwhelming for our friends with special needs and sensory issues. That is why we offer Sensory Friendly Night! The music is softer, flashing lights are minimal, the arcade is turned off and overall, the distractions in our family entertainment center will be dialed down.

## START Annual Conference

**April 27, 2020**

8:30 – 3:30

Kellogg Hotel & Conference Center

219 S Harrison Rd

East Lansing

Registration opens December 2, 2019

<https://www.gvsu.edu/autismcenter/start-conference-167.htm>

## Touch a Truck Event

May 2, 2020

10:00 – 2:00

Mart Dock

560 Mart St #1, Muskegon

Autism Network of Muskegon is hosting a day of getting up close and personal with monster trucks and service vehicle that are typically loud and scary. Children and adult will be welcome to touch and look at the vehicles while they are sitting quietly at the event.

## Spring Fling Celebration and Banquet

May 16, 2020

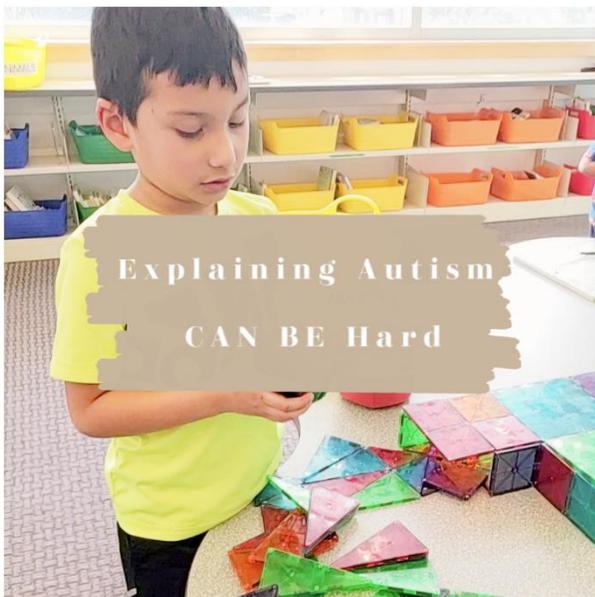
5:30 – 9:00 pm

GVSU Alumni House

1 Circle Drive, Allendale

Speakers: Author of “*Litchfield: A Peaceful Western Town*” Tate Zelman and Tina Zellman

Join us for our annual celebration of the people who make a difference in the lives of our children helping them have their best life. It’s time to start thinking about who impacts the lives of our children. Send nominations to [contact@asws.org](mailto:contact@asws.org). A short nomination outlining why this person is special in your child’s life and their contact information.



Explaining that Castiel has autism can always be a *little* bit difficult, of course, the level of difficulty depends on the type of situation I’m in. For example, am I explaining my son’s autism to an adult or a child? Are they open-minded? Do they believe that autism is a ‘real thing’? And the most important, why am I even explaining my son’s diagnosis in the first place? What’s the whole reason behind my explanation?

I always have these questions floating in the back of my head for whenever I feel an explanation is needed but I’ve discovered that most, if not all, of the time it’s way easier to explain my son’s situation to adults than it is to children. There’s just an equal level of comprehension occurring from one adult to another that you don’t get when there’s a conversation happening between an adult and a child.

Even though there’s a possibility that the adult I’m explaining my son’s diagnosis to will leave our conversation not fully understanding the diagnosis they’ll at least leave with some form of understanding about what the diagnosis is like for my son. Which is way more than I can say about the conversations I’ve had with children about Castiel and autism.

Does this mean I’m going to stop trying to explain autism to kids?

Nope, I’m going to keep trying because although I struggle with explaining it, I like the fact that kids are curious enough to ask me questions about the differences they notice between Castiel and them. It’s an opportunity for me to expose

their minds to the world of autism. To explain that yes, autism exists, yes it can *look* normal but it is still different from 'normal', from children like themselves.

I also try to explain that it's ok for them to be scared of Castiel and some of his actions or mannerisms because he can be a bit scary from their eyes or from their perspective. I mean here's a kid who looks like them but he's waving his hands and dashing across the room back and forth, over and over again. So, for kids who have never been told about autism or known someone with autism, those behaviors can come off as a bit frightening to them.

### **Meet Scarlett Cruz**

I am a mommy to 2 boys, Castiel & Ezekiel, Cass has autism. He has opened my eyes to the beauty of his diagnosis but I have also experienced the unknown of his diagnosis as well. I hope my blog & YouTube channel can be a haven for concerned, curious parents & act as a source for information & answers to autism. With love, Scarlett

Scarlett will be a ongoing guest contributor to our newsletter but if you don't want to wait for her next article feel free to read her writing on her blog.

[www.unknownseas.com](http://www.unknownseas.com)



[https://www.youtube.com/channel/UCDh28yAh9gXhk-yTgYGQoFw?view\\_as=subscriber](https://www.youtube.com/channel/UCDh28yAh9gXhk-yTgYGQoFw?view_as=subscriber)

## **Resources: Camps**

<https://www.kidscamps.com/camps/michigan-specialneeds-camps.camp>

<https://www.asws.org/summer-day-camps>

## *Message from the Board, ASWS: A great place to belong*

*When our son was diagnosed with autism more than 20 years ago, I felt so alone. I didn't know anyone who had a child like ours, a beautiful boy who was more fascinated with watching a clothes dryer than playing with toys.*

*A newspaper article led me to Autism Support of West Shore. Back then, it was known as the Autism Society of West Shore. This tight-knit, welcoming group embraced our family. After a few heartfelt conversations, I knew that I had made lifelong friends. We were a small operation; sometimes, just a handful of moms around a kitchen table. "Grassroots" doesn't even begin to describe it.*

*It was a place to belong.*

*I wish that I could say that years later, I have all the answers. I don't. If anything, I have more questions than I did on that fateful day when we received a diagnosis that would change our lives forever.*

*What I do know is that the worst feeling in the world is feeling alone. While it has been written many times that there is death in the diagnosis, there also is an ongoing, pervasive isolation. With another child, there might have been Saturday morning soccer games, sleepovers and a calendar full of play dates. With my child, there were hours spent in therapy, miles driven in our faithful van, and the occasional knowing nod of another mother in the waiting room.*

*I took great comfort in the safety net that ASWS provided. My family could attend social events without judgment. We could listen to speakers to educate ourselves about autism, and in turn, educate others. We could attend coffees and exchange ideas with other parents. The ASWS Spring Fling gave us the opportunity to recognize those who made a difference in our son's life. The Puzzle Run gave our son with autism the chance to use his love for running to support a great cause. The golf outing raises much-needed funds for family and educator scholarships. I am a miniature golf enthusiast, but I love the 19<sup>th</sup> Hole Party.*

*I am forever grateful for every encouraging word that I've received over the years from the fantastic parents in ASWS. These parents lifted me up, and kept me going.*

*If I had to describe ASWS, I'd say that it is a great place to belong.*

*Susan Judd*

*At-large board member*

