

Proud Aspy Mom Newsletter | November 2020

Where the "S" on your chest with pride!





Last month I shared my family's journey with our daughter who has Autism Spectrum Disorder, (ASD). It was the first time I shared my story in a candid way. In the past month, I have received many phone calls, emails and text messages thanking me for the content and asking for more supportive resources. I want to again reiterate to anyone caring for a loved one amid COVID to take care of yourself and allow yourself to breathe. Nothing works well if you are not up for the task. Give yourself the space to breathe and regenerate.

Stress impacts you, but also sets the tone of your household. Last week when Hurricane ETA was on the horizon, I was reminded by this simple rule that my daughter's occupational therapists explained to me years ago. Now, along with the weekly fatigue of overscheduling and providing supports we have a storm to address. Along with ASD, my daughter has Sensory Integration Disorder. This disorder makes ordinary occurrences excruciating. Sounds we "filter out" she "filters in." Ordinary spaces with noises others do not hear ring full volume in my daughter's ears and while it is hard to describe, she has a sixth sense about the weather. It either calms her or sets her completely off. The best way to describe it is with this video of a child walking through a mall. It demonstrates the level of strength it takes for a person with ASD and Sensory Integration Disorder to go about their day to day lives.



Can you make it to the end?

Understand autism, the person and what to do. I'm not naughty. I'm autistic. For autistic people like me, the world can be a terr... www.youtube.com

So, now we have home-school responsibilities, COVID, isolation and a hurricane. Nice-right! After lamenting about the week, I soon was reminded that my daughter has the skill set to deal with her world and it is my continued responsibility to help her cope during a complex time. For the many parents who reached out to me this week here is what I would share with you.

1. Have a sensory break space. Create a space in your house or at school if permitted that serves as a place of safety.

2. Have a plan for the inevitable. For some this means headphones or earplugs, for other fidgets, for many weighed blankets and for my daughter that means books to distract her from the sensory moment.

3. Water works! A warm bath, with bubbles, salts and soft music decompress quickly.

4. If you have access to a pool or unique programs like surfing- it will change your life.



Surfers for Autism

Surfers For Autism is a non-profit organization that helps to open up new potential in kids on the spectrum, by providing a fun filled day in the water. All merchandise sales go toward helping to keep our events free to families. Read More

Also check Out Beach/Surf Therapy

5. Massages work. Deep pressure with lavender or other calming oils calm the senses quickly.

6. Have an exit strategy. Sometimes none of the above work and allow your loved one to "get it out of their system" and reset!

Do not worry about what others have to say. Let yourself breathe and wear the "S" on your chest with pride and please keep the questions coming.

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The Unbearable Sensation of Being: Living With Sensory ...

www.ucsf.edu

Learning Loss - and 2021



Any parent worries about the educational path of their child. We also constantly worry if we are doing enough. I recently have been exploring the depth of Learning Loss and what that means for our ASD students in 2021. The truth is loss is real and now is the time to pivot and find innovative ways to step in the gap of services. Special needs students currently miss services they are entitled to under law but cannot enforce in any meaningful way. Each school district must balance how they deliver services

and further grapple with how they will address significant regression when students eventually return to the classroom. As we balance educating our students and keeping up with their academic requirements, we must not forget the importance of socialization.

For those with ASD, connection is essential to progress. Isolation forces those with ASD further into their own worlds, making it difficult to re-connect with others. Moreover, many people with ASD do not have a strong social network of friends. So- when opportunities arise to connect with peers, families must balance the risk of COVID with the need for social integration.



I had to make the difficult decision to allow my daughter to go back to some semblance of normalcy. While it weighs heavily on my spirit, I now believe that having a social opportunity in some cases is more important than sitting for a zoom class session. I applaud the creative ways many teachers implement education. However, we cannot replace the impact of a simple human touch. My suggestion is to try and manage as best as you can. Cooking lessons, pottery lessons, robotics and sewing allow the brain to work harder to suppress the stress of the moment.

We will not be here in this COVID space forever, but while we are it is ok to

accept the Learning loss and live a little. When we go back, however, be prepared. Do your research! Know your rights! The Florida Department of Education has a manual that educates teachers and parents. As you prepare for 2021, arm yourself with information and know who to call to share your voice.

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