

Autism Support of West Shore

A place where everyone fits



January 2020

Volume 2 / Issue 1



*To all our families and friends,
ASWS wishes you a wonderful 2020, where you remember to laugh at the absurd moments in our life (can't make this stuff up!), shed a tear when you need to relieve stress, connect with a friend who has "been there", and especially find joy every day, even the hard ones.*

Growing Personally and Professionally from My Son's Asperger's Syndrome

David Urban

I can remember when, after nearly two years of confusion regarding the emotional unravelling that had plagued our beloved older son, Daniel, since his sixth birthday, health professionals confirmed that Daniel had Asperger's Syndrome. Only weeks before, I had never even heard of AS and knew nothing about it. To say the least, I had a steep learning curve, but the process of understanding Daniel's AS greatly helped me be a better father to Daniel. It helped me realize both the many ways I wasn't parenting him appropriately, and my need to regularly ask his forgiveness for my past and continued failures to raise him in loving understanding. It helped me realize the need to prayerfully and strategically commit to his long-term betterment in a way that addressed his concrete needs instead of floundering in the frustration of my earlier ignorance.

But learning about Daniel's AS also helped me better understand various other life challenges. At the time of Daniel's diagnosis, my mother's health was declining, and she died several months later. I had always loved my mother deeply but also experienced great frustration because of her disorganization and tendency to make socially inappropriate statements. In the months just before her death, that frustration transformed to a deep sadness accompanied by the shame of realizing that I had judged unfairly a dear woman who, I finally recognized, had lived her entire life as an undiagnosed person on

the autistic spectrum. This realization also gave me greater respect for my father, who amid his own confusion had lovingly endured her idiosyncrasies and often patiently responded to my youthful frustrations by telling me, “She can’t help it, David. She just can’t help it.” I came to lament that neither of us knew how Mom’s condition could have been addressed in ways that might have modified her problematic tendencies while empowering her many undeveloped gifts.

And certainly, Daniel’s AS diagnosis has helped me understand my own lifelong quirky behaviors. My own undiagnosed AS is more borderline, but its reality helps explain my seemingly endless forays into eccentric humor, a practice that gained me (in addition to numerous detentions) the Best Sense of Humor award as I graduated from junior high school and eventually morphed into my longstanding persona as a quirky, absentminded English professor. Now understanding myself more clearly, I am better able to recognize how I can monitor my humorous proclivities so that they are more comprehensible to a neurotypical audience.

Recognizing my own condition has also helped me better cope with my organizational challenges. For as long as I can remember, I have been remarkably slow to collect my belongings and transition to a new location. My borderline AS helps explain this tendency. After I gained the courage to explain my condition to the chairs of my department, they accommodated me by allowing me to stay in the same classroom for consecutive classes instead of assigning me to a different room for a different class. I’ve also adjusted by conducting student appointments in my classroom after finishing teaching instead of returning to my office for such meetings.

It has now been more than eleven years since Daniel’s diagnosis, and I rejoice and say that he has grown consistently in his social skills, his work ethic, and his overall emotional and spiritual maturity. Our mutual journey is scheduled to take a new turn next fall when he is scheduled to begin his freshman year at my university. I’m definitely hoping that he takes one of my classes and that he demonstrates his patience toward his father by laughing at my jokes.

Winter 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 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.

February 22, 2020 2:00pm

Parsons Dance (10 tickets remaining)

The exuberant personality and joyous movement of Parsons Dance fuses the movement of modern dance with the

discipline and precision of a classic ballet company. Known for engaging and uplifting works of incredible artistry, Parsons Dance was formed by dance legend David Parsons, whom *The New York Times* called "one of the great movers of modern dance." This athletic ensemble creates a spirited evening of dance for all ages. "Parsons and his company are one of the hottest tickets in contemporary dance. They are all terrific performers, energized. Parsons provides choreography that's consistently intelligent, witty, well-crafted, and humane." -*The Toronto Star*

March 15, 2020 1:30
Dog Man the Musical (3 tickets remaining)

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 (10 tickets remaining)

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.

LAMP for Patrick

Chris Howell

About 9 months ago, our 12-year-old son Patrick received a brand-new iPad equipped with the Lamp Words for Life application. For those who might not be familiar with Lamp, it is a customizable communication app that allows its users to touch pictures on the screen to generate a verbal response. Essentially, this application acts as a nonverbal child's voice.

Aside from the occasional sporadic word, Patrick is for the most part nonverbal. Throughout the years, we have used PECS (Picture Exchange Communication System) and sign language with limited success. PECS seemed to work well however, the picture cards were easy to lose and became damaged quickly. Although we haven't taught Patrick any additional sign language since giving him the Lamp iPad, he still signs nearly daily when his iPad is not readily available to him.

After eight months of use, we believe the Lamp software has proven to be very useful. Patrick has always been relatively strong when it comes to receptive language however, his inability to form words is obviously frustrating for him. Lamp seems to bridge the gap nicely and is clearly more convenient and practical than PECS and is easier to learn than sign language. Prior to receiving Lamp, my primary concern was that Patrick may lose his motivation to attempt to verbally form words because he had an easy alternative. This remains a concern although the rewards of using Lamp seem to outweigh this possible side effect. Additionally, I should note that we still hear Patrick make verbal requests sporadically so perhaps my concerns were unsubstantiated.

Not long after Patrick received his iPad, he learned how to verbally protest ABA therapy. Prior to receiving Lamp, Patrick protested by laying down and refused to get up. Now, when his ABA therapist arrives and he's not in the mood to "work", we hear a string of words coming from the iPad that goes something like, "Bad, bad, leave, leave, leave, bad, bad." I suppose we shouldn't encourage this sort of behavior but it shows useful communication which is hard not to be excited about.

The only downside to utilizing Lamp that we have seen so far is its cost. The software cost about \$300 which is more than an iPad however, if you're considering purchasing this application, they do occasionally offer discounts. Moreover, with over 3000 symbols and words in the Lamp application, it's easy to justify that cost. Additionally, I believe you will find that speech therapist will unanimously agree that iPads utilized to run the Lamp application should be for the Lamp

application alone. Patrick's iPad has been programmed with guided access which automatically goes to the Lamp main screen immediately after being turned on.

If you are considering purchasing an iPad and the Lamp App. or any other communication software a protective case is a must. Finding the right case has proven to be the most difficult part for us so far. There are literally hundreds of protective cases available however, Patrick likes to disassemble things and he is a pro at it. There are cases available with straps that go around a child's neck however, Patrick finds these straps to be difficult due to sensory issues. Ultimately, we have forgone cases with straps and gone with one that is nearly impossible for Patrick to disassemble, at least until he figures out where I store tools anyway.

Save the Date

Social Gathering

January 15, 2020

6:00 – 8:00

Panera Bread

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.

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>

2020 Navigating Autism Today Conference

March 6, 2020 @ 8:00 am - 3:00 pm

Wayne County Community College – District, Ted Scott Campus *Road*

Belleville, MI

Autism heroes from around Michigan will gather to discuss, connect and learn through participation in breakout sessions, panel discussions and interaction with a diverse mix of autism-focused exhibitors. Parents and Caregivers: Free | Professional Fee: \$50 Register <https://autismallianceofmichigan.org/event/2020-navigating-autism-today-conference/>

Access Expo for People of All Abilities

March 18, 2020

4-6 p.m. –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

START Annual Conference

April 27, 2020

8:30 – 3:30

Kellogg Hotel & Conference Center

219 S Harrison Rd

East Lansing



Resources

State Funded Initiative: Michigan Alliance for Families (MAF)

START CONNECTING December 2019

Stacie Rulison, M.Ed, BCBA

<https://www.michiganallianceforfamilies.org>

The Michigan Alliance for Families (MAF) is a statewide parent resource agency supporting families of children with disabilities and their involvement in their child's education. MAF maintains regional parent mentors across Michigan who themselves have a family member with a disability. Every staff member promotes parent advocacy and is trained in helping parents support their child's education. Families or professionals can contact their regional parent mentor with questions related to disabilities, special education and related services, and navigating the special education system.

There are a number of resources provided by MAF, including a website with specific information about special education topics, webinars, a YouTube channel with useful videos related to special education, and a number of special education-related events and workshops across Michigan.

Family involvement is very important to any child, and for children with disabilities a family's involvement in their educational experience can help with their own learning and advocacy and improve their child's learning and overall outcomes.

Teaching Exceptional Children

<https://journals.sagepub.com/toc/tcxa/current>

Some Thoughts Are Worth Repeating

As 2019 ends and 2020 comes roaring in it seem appropriate to reprint portions of an article by Kaarin Anderson Ryan, PhD, BCBA, called **Making Time for Yourself (Reprint from 6/2019)**. As parents, grandparents or care providers we get so caught up with making the holidays the best for our families and especially for our children on the spectrum that we forget to take a breath and take care of ourselves.

Although it might not be something parents pay as much attention to while they are raising kids in a busy world, there are many things available in our communities to help adults with their work-family-self balancing act. Before we get into some of those ideas, let's spend a minute to consider why it is important to fit time for yourself into the agenda.

We have all heard that you can't take care of other people unless you take care of yourself. As common-sense as this is, often busy parents put this on the back burner or ignore this logic. Think about going on an airplane. One of the first things they say to you during the essential safety lesson is that if the oxygen masks are needed the adult needs to put on his or her oxygen before helping a child with the mask. Why? Because if you run out of oxygen, you can't help your child. In daily life it isn't as dramatic or critical, but it is the same concept. If you run yourself ragged, you aren't going to be the parent you want to be. By taking time for yourself, you may essentially reduce your own stress so you can be more effective in your parenting, you may be more likely to take better care of your health by doing things for yourself, and you are being a good role model for your kids by showing them a positive work-family-self balance. If you think about your kids 20 years down the road, do you want them to continue to make time for themselves? Show them how to do that by doing it yourself.

Here are 10 ideas to help you make time for yourselves. You may choose solo activities, doing things with friends, or sharing time out as a couple. If you have a hard time finding child care to make time for yourself, consider a babysitter, respite service, a family member, or a mother's helper to give you a break. In some cases, you may need to take some

time to yourself only at the end of the day when the kids are in bed, but even on these days it is important to make the most of the little bit of quiet time in the evening.

1. Treat yourself to a coffee, meal, or glass of wine with a friend. A little bit of adult conversation can go a long way!
2. Exercise. Go for walks or hikes, take a run, go to the gym, sign up for a yoga class. Any physical activity will benefit your body, mind and spirit.
3. Look for adult classes in the community. There are numerous free or low-cost classes, including art classes, cooking classes, and library programs to meet every interest.
4. Take some time just for yourself. Read a book for 30 minutes a day, or watch an episode of your favorite show, or just enjoy the sunshine with a few minutes outside.
5. Plan a date night to help both parents rejuvenate and reconnect.
6. Plan a game night or cookout with another family. This will give your kids time to interact with peers while you socialize with your friends.
7. Consider something to pamper yourself – a manicure/pedicure, a facial or a massage. These types of activities can reduce stress and help you re-energize.
8. Join a parent group, especially if you have kids with difficult behaviors or special needs. Connecting with other parents who have similar challenges can be affirming and helpful.
9. Indulge in one of your favorite treats – some nice chocolate, ice cream. or another special item you don't normally let yourself enjoy.
10. Journal. Sometimes writing down the things that happen during the day can be a therapeutic tool for processing everything that happens in our busy lives. For some people, journaling can help plan and organize thoughts for the upcoming days and can also let off steam about frustrating events or situations. Journaling can also be used to help us remember the things that have gone well, the things we are thankful for, and the things our kids have done to give us joy.

3 Ways I Build Strong Relationships with My Student's Families

Kelsey Smith Special Education Teacher, Nashville, TN

pubs.cec.sped.org/3-ways-i-build-strong-relationships-with-my-students-families/?utm_source=cec&utm_medium=email&utm_campaign=CECatalog&_zs=1E0Qg1&_zl=6e1K6

1. Leverage local resources

If you are in any mid- to large-sized city, chances are a quick google search will reveal multiple community resources geared towards supporting families who have a child with exceptionalities. Even if you are in a more rural town, it's still worth searching and seeing what is available in your area!

There are numerous private non-profits dedicated to specific disabilities, churches or religious organizations, AND state agencies that seek to support families caring for a child with disabilities. These outside organizations are AMAZING and it is their literal mission and goal to support families! Compiling a list of these organizations and sending it out to parents is a great first step in empowering your students' families. You also can visit these organizations' websites about once a month or so and feature upcoming events or available *resources* in regular communication to your students' families.

2. Create routine communication

I know all of us have the best of intentions when it comes to communicating regularly with families! However, things get busy, life gets crazy and it's easy to let this aspect of our jobs fall by the wayside.

Help hold yourself accountable by creating a communication routine. Even if it's just a monthly newsletter, that is 10 times a year a parent is hearing from you and getting valuable information about their child's education! This is a relatively small effort for massive rewards.

Your communication doesn't have to be cute, so don't spend too much time worrying about the format or getting it perfect. Simply decide what you want to convey and how often, and work on writing that out at the necessary intervals. You could have a community resource focus, a "what we're learning in the classroom" focus, or even an evidence-based

practice focus (or a combination of the three). There are so many options here and whatever you decide may really help a family out!

3. Be proactive and positive

Parent communication doesn't have to be anything major or earth shattering! A quick two-sentence email, a post-it note on a take-home folder, or even a phone call goes a really long way. Keep this communication positive and encouraging, and share all the great things you see happening at school!

Routinely sharing positive communication with parents builds trust, creates strong relationships, and communicates that you care about their child and are 100% on their team. This will help make any discussion about a more difficult issue so much easier down the road.

Message from the Board,

I was once challenged to embrace the word "incredible" at a conference I attended. The speaker talked about how just by adding the word incredible to an experience we could actually find something amazing in it. Good and bad it's really all incredible. That tantrum was incredible – what lung capacity he has! That shoe flying past my head showed me the potential for a future shotput athlete. That thought was one of those mind-blowing experiences. She was right! It's all in how you look at something. Sometimes things are horrible, incredibly horrible, but you will survive and this is just a moment. Sometimes things are wonderful, incredibly wonderful, and this too is just a moment. It's all life.

Writing the first message of the year is always hopeful. It's a new beginning. It's a time, not to forget the challenges of the past but to embrace moving forward, expecting incredible things for ourselves and our children. If we raise our expectations, we increase the potential for incredible outcomes. I don't make resolutions anymore. I expect the new year to make me wiser than I was last year. Hardships and challenges are now viewed as opportunities to appreciate the good and near perfect moments when they come. So, enjoy and celebrate the beginning of 2020, may it be more than you could have hoped for and filled with "incredible".

Happy New Year,

Linda Elenbaas and the ASWS board