

Autism Support of West Shore

A place where everyone fits



September 2019

Volume 1 / Issue 9



FOUR!

It's that time of year for our annual Golf Outing and Auction. Love to golf? Join us September 21st, at Oakridge Golf Course for golf or our 19th Hole party and auction. There are still team slots open. Love a great party? No golf skills required! Come out at 3:00 to join the 19th Hole Party and Auction. Everyone is welcome. For more information go to <https://www.asws.org/events>.

AUT-OSOPHIES!

Shelly Boeve

Tonight I watched the episode of "Modern Family" where Phil and Claire take Hailey to college. Phil had made a hardcover book of his "Phil's-osophies" for Hailey to take to college with her. It made me think on the "Aut-osophies" of having raised a child with autism to adulthood. Here are a few, very random, observations I've made along the way: (in no particular order)

- You may prefer to deal with your feelings by putting yourself into action mode. I researched, I read, I networked, but I didn't do much grieving initially. I don't know if this is a typical parent reaction, but it is how I coped.

- The developmental gap widened as time went by. When diagnosed, our daughter was not at peer appropriate developmental level, however, with the advancing of time, the gap widened. This is when I started grieving.

- Expect your friends might change.

Throughout the first year of surgery, diagnoses, hospitalizations and coming to terms with it all, our friends stuck by closely. Not so much year 3, 4, 5. . . As time went by, we found a whole new group of friends that totally got it! Special needs parents! They were always supportive, understanding, gracious and had a listening ear for what we were going through.

- After a while, all the things you feared stopped being so important.

Toilet training – never happened; talking – never happened; mainstreaming or inclusion – never happened; independent living – never happened, and do you know what? It was OK. We learned to love Melissa for just who she was. We dropped the expectations and were the happier for it.

- You have to be a Pitbull about getting services. So be a Pitbull – not a martyr!

Your best source for discovering what services your child may be eligible for is other parents. Talk to many. Join support groups. Start one if you need to – I did and we met for 10 years! Once you know what is out there, ask, ask again, insist,

write letters, ask physicians to write letters, apply for scholarships, ask neuro-typical child services to make accommodations to allow your child to participate. When our daughter “outgrew” church nursery at age four, I asked them to start a special needs classroom or supply helpers to include her in age appropriate classrooms. A whole special needs ministry, with paid staffing, has arisen from this request. People are usually eager to assist a child with special needs, but they need to know what you need from them.

- You’ll be so proud of your child.

I remember before having a child with special needs, encountering a mom of a son with Down syndrome. She commented that she was so proud of her son. I found that interesting to the point that I still remember it. It hadn’t occurred to me that you would be proud of a child who couldn’t achieve what you’d hoped. Then I had my own child with a disability and I totally got it. She worked ten times harder to achieve what came naturally to neuro-typical kids. She never gave up and I was so proud of each achievement and how hard she worked to get there!

- Avoid the roller coaster mentality.

I finally learned that the bad times wouldn’t stay so bad and the good times wouldn’t stay so good. I remember being thrown into despair with each new bout of insomnia or being over the moon when an achievement was made. I had fallen into the trap of “It’s always going to be this hard” or “We’ve finally turned the corner!” Neither was true. I had to learn to modulate both my despair and my elation into a constant reminder that this was now, but tomorrow, next week, next year, or 10 years from now, things would be different. This saved a lot of emotional energy.

- Whoever is close to you that thinks they “get” your life, doesn’t.

There is a sorority of special needs moms. No one else gets it. Not even the dads (they can have their fraternity!). Doesn’t matter if it’s autism, a physical or cognitive disability, or all of the above, they understand. There is a bond there!

- What your other children give up, is more than made up for.

Your disabled child’s siblings will make sacrifices. There’s no getting around it. But what they gain over the course of a lifetime will more than compensate for that. I’m talking decades later. They will be shaped by watching your advocacy, patience, love, and tenaciousness! It will make them better people and better parents.

- Having a child with special needs will change who you are.

I often reflect on how difficult this road has been and invariably end up by looping back to, “But who would I have been if I hadn’t raised her?” I think I would have been a much shallower person. Raising Melissa has given us depth of strength and character we wouldn’t otherwise have had. Partly by watching her and modeling her strength and partly from the deepening of our faith, on which we’ve relied heavily.

- Appreciate those who help you along the way.

I try often to voice or express appreciation for the oh-so-many helpers along the way. The classroom teachers and parapro, the bus drivers, the Sunday School teachers, the case workers, caregivers, the medical staff at her doctor’s office, your husband, your kids! Notice what they do for you or your child and thank them.

- Have a sense of humor with your child.

Sometimes you just gotta laugh! Find the humor in a difficult day. Appreciate a great day! Bring up an old story of a funny situation and laugh about it again. It’s good for everyone!

- Have grace with your spouse.

The stress of raising a child with special needs can wreck a marriage, but it doesn’t have to. Your spouse’s way of interacting with your child will look much different than yours. That’s ok. Let him find his own way and they will develop their own special bond. Out of necessity, I involved my husband much more in the care of our daughter with disability than I had with her two older sisters. There’s nothing he can’t handle now! I’m talking field trip notes, snack baking, teacher communicating—he does it all! He is in charge when I go away for three weeks to visit the grandkids out of state. If I hadn’t given him room in his own way to build relationship, he wouldn’t have been equipped to do this. We

don't always agree on decisions regarding her care, but I do hold his opinion in equal weight to mine. He's certainly earned that right!

- Lower your expectations.

My "good housekeeping" went right out the window after my daughter was born, and you know what? It was all fine! Choose clutter-free OR clean. You probably won't get time for both! We lived very simply in a small home so that I could work part time. That won't be the choice everyone makes, but at least consider it. Downsizing gives you freedom to make choices you might not otherwise have.

- Find a mentor mom.

Find a mom you admire who has been on this "special needs" journey longer than you and ask them to mentor you. If they're still in the trenches of care, it might not be a formal, time-rich relationship, but it will give you someone to call when you need to cry or vent or rejoice and it will give you a different perspective you haven't yet had the time to gain. It will also equip you to be that mentor mom to the next generation of special moms coming up!

- Take care of yourself! Ha! This one always makes me laugh!

Well, at least do the best you can to treat yourself well. Indulge in a good cup of coffee or piece of chocolate. Pull out a good book and read, even if it's just for 10 minutes. Make exercise a priority. I know it seems like a chore, but the endorphins really do help! And also, give you the luxury to indulge in that second piece of chocolate! ☺

- Life goes on after great loss.

I had a mental list of things we'd never get through. Raising Melissa, the loss of Melissa's dear grandma, Melissa leaving home to live at an adult care community. They all happened. We got through them all. God gave grace when grace was needed. I worried for months and years before these things actually happened and when they did, I found most of them went better than I had expected. I didn't say easier, but better. We just got through them with time and prayer.

- You won't always be this hands-on. Rest will come.

Raising Melissa, I rarely looked past the time of her living at home. She has now lived at an adult care community for four years. It was the hardest thing we have ever done. We literally had to learn—and are still learning—how to be a couple again now that we are empty nesters. We are learning to appreciate the freedom and we are also learning that based on Melissa's and our needs to still be highly connected, we don't have as much freedom as most empty nesters. We don't take long vacations away together because Melissa depends on seeing us several times per week. We spend a lot of time together yet. That's OK. It may be this way forever and it may be for a season. I've learned about life that nothing ever stays the same.

I hope I haven't made this long, arduous journey seem too over-simplified. It's the hardest thing ever. It's left me with some honest-to-goodness PTSD. The demands were just greater than the ability or the energy so much of the time. My goal in sharing these thoughts is to give you a more global perspective on this journey versus the micro-vision perspective we find ourselves in when we're in the middle of one of the most demanding times of our lives. I have so much respect and admiration for each of you doing the hard work of raising little ones with extra need. God assigned you this little one. He will equip you. Ask Him every day for provision and wisdom and then live life assured He is on this journey with you!

Save the Date

Michigan Self-Advocacy Summit

September 11th, 2019

Lansing, Michigan

https://ddi.wayne.edu/brochuresflyers/self-advocacy_summit_registration.pdf

Autism 101

September 18, 2019 Autism 101

6:00 – 7:00pm

This presentation is appropriate for: parents or caregivers of children and young adults who have been newly diagnosed with an Autism Spectrum Disorder (ASD).

Register <https://brainspotential.com/autism101registration/>



ASWS Annual Golf Outing and 19th Hole Party

September 21, 2019

Oakridge Golf Course

<https://www.asws.org/events-1/asws-golf-outing>

Family Fun Day at Craig's Cruisers

September 22, 2019

3:00 – 5:00 pm

Join us as we kick off fall with an afternoon at Craig's Cruisers on Pontaluna in Norton Shore.

Rides and activities for the entire family and token packs for all children. Register your family attending at:

<https://www.asws.org/events>

Charting the Lifecourse Community wide Event

September 24, 2029

Trestle Stop Restaurant

3366 M-40, Hamilton, MI 49419

9:30am-12:30pm

Do you believe all people have the right to live, love, work, play and pursue their life aspirations in their community? If so, we invite you to join us as we provide an introduction to Charting the LifeCourse, a framework designed by and for individuals and families at any age or stage of life to think about what they need to know, identify how to find or develop supports, and discover what it takes to live the lives they want to live. We will demonstrate how three tools developed from the framework can be used to have meaningful conversations with individuals to plan for present and future life outcomes that take into account all facets of life and have life experiences that build on self-determination, social capital, economic sufficiency and community inclusion.

Please see the attached flyer for more information. Registration is required. Please visit <https://www.surveymonkey.com/r/NGV2NKW> to register. Space is limited!

Holland Aquatic Center

September -October

Fall Special Needs Swimming Lessons Class time 5:45-6:25

<https://hcac.recdesk.com/Community/Program/Detail?programId=1214>

The Special Swim Learn to Swim Course is focused on providing swim instruction to those with unique needs. Beginning with basic water adjustment skills, students work towards floating and independent swimming with trained volunteers. Parents are welcome in the water but not required.

Emergent Literacy Instruction for Students with Significant Disabilities and Complex Communication Needs

October 1-2, 2019

Students with significant disabilities can and do learn to read conventionally with supportive print- and language-based experiences and interactions. Not unlike students without significant disabilities, this learning for students with significant disabilities begins with emergent literacy. Students who are emergent literacy learners should be provided many frequent learning opportunities that provide instruction and practice with functions of print and print conventions, phonological and alphabet awareness, and expressive and receptive language skills. This training is based on the work of Dr. Karen Erickson and Dr. David Koppenhaver.

<https://www.altshift.education/event/emergent-literacy-students-significant-disabilities-0>

Autism and Anxiety

October 21, 2019

6:30 – 8:00 pm

Herrick District Library, Holland

Autism Support of West Shore will be hosting Dr. Kaarin Anderson-Ryan as she speaks about Autism and Anxiety.

Peer to Peer Statewide Training

November 5-6, 2019

8:30-3:30

Kellogg Hotel and Conference Center

219 S Harrison Rd, East Lansing

<https://www.gvsu.edu/autismcenter/start-events-49.htm>

Back at It

School is back in session! While some of us might be doing a happy dance there still is that heart tug as you watch your child head off to another year of school. New teachers, some new friends, lots of new experiences and new challenges. As parents we know that this is the natural progression of things but often the natural progression looks very different for our children. As our children grow older, we notice new stresses, bigger challenges and some good old typical teen angst. As parents it critical that we help preserve our children's self – esteem. Created by the Positive Psychology Program, 6 Self – Esteem Activities for Teens is a great resource for teaching our children how to maintain a balanced self-image.

6 Self – Esteem Activities for Teens

Affirmations

1. Start with the words "I am..."
2. Keep them positive
3. Keep them short and specific
4. Keep them in the present moment
5. Include a "feeling" word about yourself

List your wins in

- The first phase of your life
- The second phase of your life
- Recent successes
- Successes you want to achieve in the next five years

Self Confidence

1. Think of a situation in which you felt confident
2. Think of a situation in which you lacked confidence
3. Brainstorm ways to feel more like you did in situation one than in situation two

Coat of Arms / Family Crest

Fill the crest with things you value, things you love, or anything that you feel represents you

My Goals / Setting Goals:

- Something I want to accomplish in the next week
- Something I want to accomplish in the next month
- Something I want to accomplish in the next year
- Something I want to accomplish in the next five years

Obstacles and Strategies:

- Obstacles to reaching my goals
- Things I will need to do to achieve my goals
- What I can begin doing tomorrow to work towards my goals

Flipping Your Mistakes, Failures and Obstacles

Think about the mistakes you have made and the obstacles and failures you have faced, brainstorm how to flip each one, and commit to the flip.

Resources

ASWS Newsletters

Miss out on a past newsletter or want to share our newsletters? Check out <https://www.asws.org/blog> for past newsletters and post. *Coming soon on the blog Spanish newsletters.*

Michigan Alliance for Families has a DVD available: "Making the Most of *Early On*[®]", designed to help parents better understand and access the system of supports and services for children from birth through age three. This video is divided into six topics and is available with Spanish subtitles, Arabic subtitles, or English closed caption.

<https://www.michiganallianceforfamilies.org/dvd/>

Join Michigan Alliance for Families Parent Mentors for a series of FREE webinars for parents and caregivers preparing for the new school year.

All webinars take place on Thursdays. Each topic is presented twice, at noon and 7pm. Attend the entire series or just the ones that interest you most. <https://www.michiganallianceforfamilies.org/wp-content/uploads/2019/07/2019-Back-to-School-Webinars.pdf>

Message from the Board,

Finding Your Tribe

Susan Judd

By now, many of you know this story. Nearly 20 years ago, my dear son was diagnosed with autism. We knew that life with our curly-haired, energetic toddler would never be the same.

We knew we were embarking on a new journey. Acronyms like "IEP," "ABA" and "ASD" worked their way into our daily vocabulary.

And people who wanted to love and help us worked their way into our hearts.

I don't know why, but I kept a clipping from our local newspaper in my top dresser drawer for a few months. It was an article about children who were like my son, children who had autism. Their parents were forming a support group.

I had spent years as a reporter and editor, culling information from often unwilling sources. Yet this call was tough to make. I finally gathered the courage to call one of the moms featured in the article.

It was one of the best decisions of my life. We talked for nearly an hour. Our children shared the same diagnosis. We shared the same life.

I told her how my son had been designated "Most Likely to Wear a Lampshade on His Head in College" by women that I thought were my friends. I laughed it off until I got home and could have a good cry. I told her how we

were banned from one playgroup and warily tolerated in another. My son with his cherubic cheeks and sweet smile could go from being happy one minute to screaming like a banshee the next.

I felt misunderstood and unwanted. I can only imagine how my son felt. I could dress him up, hand out impressive treats and toys, and yet there was always the underlying feeling that we didn't belong.

In college, I had three close friends. We still keep in touch despite being separated by miles. We've seen each other through the best and worst of times. After my son was diagnosed, I knew I wanted, and I needed, a like-minded posse. Although I'm a fairly solitary person, I knew from past experience that it was too hard to go it alone.

Enter the Autism Support of West Shore. I knew the first time I sat around a kitchen table with a half dozen moms (the dads were home watching the kids) that I was home. Although the organization has evolved over the years, our mission remains the same — to offer support to families facing autism and to help our loved ones live their best life.

I gently encourage you to reach out. You'll find friends and acceptance, and so will your children. The journey is rough but it is so much easier to travel it with a friend.



September 22, 2019

3:00 – 5:00 pm

Join us as we kick off fall with an afternoon at Craig's Cruisers on Pontaluna in Norton Shore. Rides and activities for the entire family and token packs for all children. Register your family attending at:

<https://www.asws.org/events>