

Connecting Wisconsin

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Message from the President

Dear ASW Member:

With this, my first correspondence to you as your President, I thought that you might like to understand the roots of my service, linked to two separate events which occurred 30 years apart.

First, in 1975, I was trapped between two cars as a pedestrian. As a result, I sustained multiple fractures of the bones in my legs. The first hospital recommended amputation, so I asked to be transferred for a second opinion. Following the accident both of my legs were in full-leg casts for two months. My right leg remained in a full-leg cast for fourteen months, followed by an additional six months in a full-leg brace. As a self-proclaimed, student-advocate at the University of Wisconsin-Milwaukee, before the Americans with Disabilities Act, I advocated for better accessibility for disabled students. Over a time-span of 41 years, I have had bone-grafts from both hips, my right tibia and fibula re-built twice, my right knee and right ankle replaced, my left knee capsule repaired and the tops of four toes on my right foot amputated. Today, I ride my Trek for therapy and enjoy slow walks with my son, Harley. My wife Jody and I welcomed him into our lives in 2008. Two years later he was diagnosed with autism. With an understanding for the challenges faced by those with physical disabilities, and then my experience as a parent of a child with autism, I became more deeply committed to advocacy. Eventually, I became acquainted with the Autism Society and decided to pursue activities to become more involved and share my passion for advocacy and service.

As I sit at my computer composing this, I am very thankful for the experiences that have brought me here to you. There is no question there have been many challenges along the way. And I am a better man because of them. I have gained a better understanding of patience and acceptance. I know that, no matter what, I will find my way through it. I think we share that quality. Being touched by a disability adds dimension to my life. It keeps me grounded. It keeps me humble. And, for me, it provides a deeper sense of understanding for the realities of life. I hope it enriches your life too. I believe that sharing my experiences with others brings more to my life, in return. And I look forward to sharing more with you as we move into the future together. Please know that I would welcome your call with any questions or requests. And know that everyone at the Autism Society of Wisconsin is here to share your journey. To celebrate the challenges and to embrace the lives that have been touched by autism.

All the best,

Bob Johnston

Autism Society of Wisconsin President

Transition to Adulthood Conference Coming to Wausau this Fall!

Autism Society of Wisconsin Fall Conference
Transition to Adulthood
October 5, 2017
Wausau, WI

Fairfield Inn & Suites
7100 Stone Ridge Dr, Weston, WI 54476

Keynote Address by Dr. Carol Schall Pathways to Employment for Transition Aged Youth with ASD

Achieving competitive, community-based employment continues to be a challenge facing young adults with autism spectrum disorder (ASD). Nevertheless, there have been some studies that demonstrate successful supports for individuals with ASD. In this session, Carol Schall, Ph.D. will present research on the impact of internships, supported employment and customized employment on employment outcomes. She will also include an in-depth discussion of the behavioral methods used to support youth and young adults with ASD in the transition from school to work.

The one day conference will include breakout sessions, a panel of youth and young adults on the autism spectrum, and a resource hall. Please join us in Wausau this fall to build your capacity to support youth transitioning to adulthood.

More details will be available on our website soon: http://www.asw4autism.org/conferences_workshops.html

Contact Jessica Fischer at jfischer@asw4autism.org with questions.



Autism Isn't So Strange

By Zach Shariff

I recently graduated from University of Wisconsin Green Bay with a bachelor's of arts in Political Science and Philosophy (with a global studies minor.) During my last semester I took on the task of doing an independent study paper for a philosophy class. Ironically my paper topic was on the ethics of disability rights. It resulted with an A grade (the highest UWGB can give.) The paper was 23 pages long, and took me the whole of the semester to write, not to mention that I had to sift through well over 1000 pages of text from various text books to find the material needed to complete it. I did have occasional assistance from two professors in the philosophy and political science departments. However as per the expectations of the study, I did pretty much all of the work single handedly, only asking for help when needed, which wasn't terribly often.

The paper itself highlighted that disability is not a disease, its not purely a negative thing indicatively, after all, autism doesn't belong in the same category as cancer or ebola. And disability is certainly not a matter of us and them, for everyone either has a disability, and even if one does not, one is still and always will be vulnerable to getting one.

What separates the neurotypical (non-autistic) from the autistic? It isn't all that substantial, people like me still have a capacity to live and possess liberty, every human has that. My brain may operate a bit differently, but as evident by my paper's success, I show that those on the spectrum can certainly succeed at something most would struggle to make any headway in at all.

Autism isn't a purely a positive thing, there exist negatives. But what exactly is normal anyway? Heart disease, family history of colon cancer, asthma, and a mild skin condition; all of this is within the range of what many consider normal. Heart disease is far worse than autism and far more common, normalcy is thus little more than commonality, something is "normal" because a lot of people have it. Not to mention that quite a few "normal" people display amoral behaviors, like lying, cheating, backstabbing, and that certainly isn't good either. Martha Nussbaum a modern philosopher put it best, that in addition to commonality, there's the fact that the healthy "normal" state of wellbeing many enjoy, is actually quite fleeting. Eventually one grows old, and may require assistance. So being human, it seems, already entails baggage, whether you have autism or not.

Alas, a better way to look at autism, is not as a disease or mental defect, but rather by the individual traits, positive and negative. In the case of the positives, there's hyper focus, mind specialization, spatial awareness, and visual thinking; and trouble socializing and a tendency towards difficult communication existing for the negatives. So for those living with it, especially those who're unsure, shouldn't be ashamed of themselves, they ought not look at themselves as pathetic. The reason autism might seem like a complete negative, is largely because of the way people have perceived it and portrayed it. As many people are generally, and historically have been uncomfortable with things that seem strange or unfamiliar to them. And take it from someone who has it, it isn't all that bad. Is it a disability, yes, because negative elements are present, but so are positives, and that's why it's not a disease.

Next Step Project Announcement

In Partnership with Parent to Parent of Wisconsin

The Autism Society of Wisconsin is excited to announce it's recent grant award from the U.S. Venture/Schmidt Family Foundation, in partnership with Parent to Parent of Wisconsin. The grant will fund a Next Step project designed to connect parents to local resources and other critical sources of support after their child has received an autism diagnosis.

A recent survey conducted by the Autism Society of Wisconsin revealed that only 11% of parents of children on the spectrum statewide feel supported by their community. Over half of parents also indicated that isolation, lack of support and/or difficulty navigating the service system were in the top 3 challenges their family has faced since their child has received an autism diagnosis. Comments from parents about challenges included, "Isolation socially from other parents/families", "Felt like we were given the diagnosis and left to figure out everything else on our own" and "Feeling alone/nowhere to turn".

As a result, the Autism Society of Wisconsin and Parent to Parent of Wisconsin have teamed up to enhance information and referral and support services offered to parents new to autism. Parents who have a child recently diagnosed, within the



Autism Society of Wisconsin 53 county service area, are encouraged to make their Next Step after diagnosis a call to the Autism Society of Wisconsin. During their phone call, parents will receive access to support, guidance and community referrals. They will also receive a free resource package and access to other parents through local Autism Society support groups and one-to-one matching through Parent to Parent of Wisconsin.

Parent to Parent of Wisconsin is a statewide agency that provides parent support to parents of children with special needs through a one-to-one connection with another parent who has had similar experiences and knows firsthand about the feelings and realities that come with having a child with special needs. By creating a network of trained support parents, Parent to Parent is able to connect new parents to experienced parents who have been down a similar journey and have received specialized training preparing them to provide support to others.

In recent years, Parent to Parent of Wisconsin's biggest request for support comes from parents of children with autism, which makes this a natural partnership. In addition to the in person support groups offered by the five Autism Society of Wisconsin local affiliates, this partnership will add another layer of support available to parents.

As part of the project, the Autism Society of Wisconsin is committed to helping Parent to Parent build their network of trained support parents of autism to keep up with the growing need.

Resource Package Contents Include:

- Next Steps Booklet: A Guide for Families New to Autism Spectrum Disorder
- Uniquely Human Book by Barry Prizant
- Gift of Hope Book by Kelly Shariff
- One Year Membership to the Autism Society of Wisconsin
- Discount to the Autism Society of Wisconsin Annual Conference

UPCOMING EVENTS

We're working on planning a Support Parent training this fall in the Fox Valley area. If you're interested in joining the statewide network of parents and families that support each other please contact us.

To view upcoming Support Parent Trainings, please visit <http://www.p2pwi.org/trainings.html>

If you'd like to receive updates on the upcoming training in the Fox Valley this fall or if you have any questions about the project, please contact Robin Mathea from Parent to Parent of Wisconsin or Kirsten Cooper at the Autism Society of Wisconsin.

Robin Mathea | rmathea@chw.org | 715-361-2934

Kirsten Cooper | kcooper@asw4autism.org | 920-215-3303

For more information about local support groups please contact your local affiliate:

Autism Society of Central Wisconsin
autismsocietycw@gmail.com

Autism Society of Chippewa Valley
cvautismsociety@gmail.com

Autism Society of the Fox Valley
info@autismfoxvalley.org

Autism Society of the Lakeshore
autismlakeshore@gmail.com

Autism Society of Northeast Wisconsin
administrator@asnew.org

August 17
6:30–8:30
pm

Swing & Swim Event | Autism Society of the Lakeshore

Village Inn on the Lake, Two Rivers

Come on over to Village Inn to play some mini-golf and then join us inside for swimming! All are welcome, and it's all on ASL! Just show up!

September 9
10:15 am -
12:20 pm

Football Camp | Autism Society of the Fox Valley

Xavier High School, Appleton

Join us for our 12th Annual Football Camp! This coed, non-contact camp is perfect for all ages and abilities! Siblings and parents are welcome on the field with the campers. A picnic style lunch will follow the camp. The camp is FREE for kids of all ages.. Visit: autismfoxvalley.org

September 16, 8:30 am

Annual Autism Awareness Walk | Autism Society of Northeast

Green Isle Park, Green Bay

Please join us for the 11th Annual Autism Awareness Walk on Saturday, September 16th. For more information email administrator@asnew.org or call 920.264.8067

September 23rd

Autism Across the Lifespan hosted by Congressman Mike Gallagher

Paper Valley Hotel, Appleton WI

Autism Advocates, family members and friends - mark your calendars for September 23. Congressman Mike Gallagher will be hosting "Autism Across the Spectrum," featuring a panel of local experts, and Judith Ursitti, Autism Speaks Director, State Government Affairs and mom to two children with autism, as the key note speaker. The Autism Society of Wisconsin will be coordinating a resource fair in coordination with the event. Details to follow.

Researchers Gain Insight into Day-to-Day Lives of Parents Raising Children with Autism

By: Adityarup “Rup” Chakravorty

Like all parents, couples who have a child with autism spectrum disorder (ASD) share the ups and downs of parenting.

A new study by [Waisman Center](#) researchers at the University of Wisconsin–Madison looks at the daily experiences of these parents to provide a more detailed picture of the strengths and vulnerabilities of couples raising a child with ASD.

“I think we can use these findings to develop more effective therapies and strategies to address potential challenges in couple relationships for parents of children with ASD,” says [Sigán Hartley](#), lead author of the new study, published this month in the [Journal of Autism and Developmental Disorders](#).

Previous findings have shown that, on average, couples with a child with ASD have higher risks of divorce and lower satisfaction with their marriages when compared to couples with a typically developing child.

“What has been missing is research that really gets at the details of what is actually happening in the day-to-day lives of these couples,” says Hartley, a Waisman Center researcher and 100 Women Chair in Human Ecology at UW–Madison.

To fill in this gap in the research, Hartley and her colleagues examined the daily experiences of 174 couples who have a child with ASD and 179 couples with a typically developing child.

Each couple kept separate “daily diaries” for two weeks, and recorded information like how much time they spent with their partners, how supported they felt, how close they felt to their partners, and the positive or negative interactions they had with them.

“These measures really let us understand how couple relationships are being altered for parents of children with ASD,” says Hartley.

The researchers found a combination of vulnerabilities and strengths. Couples parenting a child with ASD reported spending an average of 21 fewer minutes per day with their partners compared to couples with a typically developing child. That may not sound like a lot of time, but “those 21 minutes add up over weeks and months to almost 128 fewer hours spent together over a year,” says Hartley.

Spending less time together could account for why parents of children with ASD reported feeling less closeness to their partners than those raising typically developing children. The ASD group of parents also reported fewer positive interactions, such as sharing jokes, having a meaningful conversation or being intimate.

Spending less time together could account for why parents of children with ASD reported feeling less closeness to their partners than those raising typically developing children.

“Parents of children with ASD may have more demands on their time,” says Hartley. “They may have to navigate therapy sessions or manage special education or interventions.”

On the other hand, parents of a child with ASD showed no increase in negative interactions, like

critical comments or avoiding their partner, when compared to couples with a typically developing child. These couples also felt as supported by their partners as couples with typically developing children.

"These are important relationship strengths that couples who are parenting a child with ASD can build on," says Hartley. Finding ways to strengthen their couple dynamics can help their children as well. "Just like any child, a child with ASD affects, and is affected by, the entire family," says Hartley. "Developing therapies or strategies that help parents thrive and keep their relationships strong is critical for the long-term success of children."



Other authors on the study include [Leann Smith DaWalt](#) and Haley Schultz, both at UW-Madison.

This research was published earlier this year in the *Journal of Autism and Developmental Disorders* and can be accessed at <https://link.springer.com/article/10.1007/s10803-017-3088-2>

The Waisman Center is home to both a Eunice Kennedy Shriver Intellectual and Developmental Disabilities Research Center and a University Center for Excellence in Developmental Disabilities.

You can volunteer for a research study or learn more about Waisman Center research at <http://www.waisman.wisc.edu/participate.htm>.

Giving Opportunities

Invest in the future of the Autism Society of Wisconsin!

Explore all the ways to give:

- **Employee/Matching Gifts** – Many employers encourage employees to give by matching employee gifts dollar-for-dollar. Check with your human resource department to find out more.
- **Honorary** – Celebrate a birthday, anniversary or other special occasion with a gift honoring a spouse, friend, family member or other loved one.
- **Memorial** – Memorial gifts made to the Autism Society of Wisconsin are to celebrate and honor the life of a loved one.
- **Planned Giving** – Receive tax and other financial benefits while giving to the Autism Society. Plan a gift for the future by working with a financial advisor to set up an IRA Charitable Rollover, trust or bequest, or beneficiary designation on a life insurance policy.
- **Unrestricted Giving**– Give a cash donation that allows us to fund programs which need it most. Donations can be mailed to the ASW office or can be made online through our Network for Good site, accessed from our home page: www.asw4autism.org.

Autism Society of Wisconsin
1477 Kenwood Dr.
Menasha, WI 54952

Please call our office for more information on any of these giving opportunities: 920-558-4602.

Autism Society of Wisconsin
1-888-4-AUTISM (WI only)
1477 Kenwood Drive
Menasha, WI 54952

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Help us fulfill our mission!

Support the Autism Society of Wisconsin by making a tax deductible gift! All donations are appreciated.

_____ \$25 _____ \$50 _____ \$75 _____ \$100 _____ \$200 _____ \$ Other

Donations may be sent to:
Autism Society of Wisconsin
1477 Kenwood Drive
Menasha, WI 54952

We also accept donations online . Click the Donate Now button on our
homepage: www.asw4autism.org

Thank you for your support!

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ASW Board Meeting

October 21