



New insights into the day-to-day lives of parents raising children with autism

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

A recent study by Waisman researchers looked 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 strategies to address potential challenges in couple relationships for parents of children with ASD," says **Sigan Hartley**, lead author of the study.

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 gets at the details of what is happening in the day-to-day lives of these couples," says Hartley.

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, and the positive or negative interactions they had.

The researchers found that 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 much but "those 21 minutes add up over months to almost 128 fewer hours spent together over a year," says Hartley.

Parents of children with ASD also reported feeling less closeness to their partners and fewer positive interactions, such as sharing jokes or being intimate.

On the other hand, they showed no increase in negative interactions, like critical comments, when compared to couples with a typically developing child. These couples also felt as supported by their partners as did those 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 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."

To read the unabridged story, please visit waisman.wisc.edu/newsletter.htm

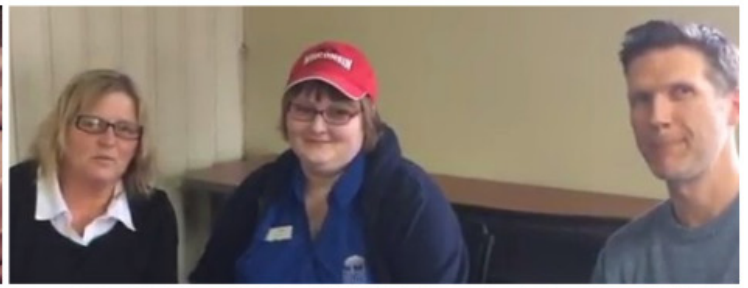


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For more than 30 years, Community TIES has helped individuals with developmental disabilities stay in their communities. To celebrate this milestone, many of those individuals and families spoke about how TIES has made a difference in their lives. Watch the video on our YouTube channel at youtube.com/user/WaismanCenterVideo

In 2017, the Community TIES program at the Waisman Center is celebrating 30 years of helping Dane County children, adolescents and adults with developmental disabilities live with their families and in their communities.



To discuss this milestone, we sat down with **Josh Lapin**, director of the TIES program, to talk about three decades of memories and successes, and

hopes and goals for many decades to come.

Waisman Center (WC): How does Community TIES support individuals with disabilities?

Josh Lapin (JL): We work with the Dane County Department of Human Services (DCHS) to ensure that individuals with disabilities have the supports they need to remain a part of their communities, with their families and friends.

I think the most important thing that we do is build relationships with the individuals we support, and with their families. Having these meaningful relationships allows us to recognize when the people we serve are doing well, and also understand why they are doing well.

Then, when things get challenging, we try to recognize those signs and subtleties and figure out how to respond and address those issues.

WC: 30 years is quite a while! How did Community TIES get started?

JL: When we began in 1986, many individuals with disabilities were leaving institutions, and they needed support to successfully integrate and live within their own communities.

Paul White, the first director of Community TIES, started with a caseload of four individuals. Today, we manage an active caseload of more than 300, which makes it more challenging to build and maintain one-on-one relationships. But our blueprint is still the same: we are dedicated to building these relationships with the individuals and families we work with.

WC: What are some of the ways Community TIES has grown?

JL: We have expanded the services we offer. We have a psychiatry clinic, now called the TIES Clinic, to assist individuals with disabilities who have co-occurring mental health issues.

We also have a Crisis Response program, managed by Axel Junker and RaeAnn Fahey. This program is for individuals who might be at risk of being taken to inappropriate mental health hospitals or prison, when it would be better for them to go somewhere else where they can cool off for a day or two or three.

Through our Rhythms Program we look at how mindfulness and technology can enhance the lives of individuals who experience complex sensory and movement differences and those who support them.

WC: Any thoughts on TIES' 30th anniversary and for the future?

JL: I think our longevity is crucial for the individuals we serve. We work with people of all ages, and you never age out of our programs.

As people get older, as families pass on or move, sometimes we are the only constant for those we serve. It's something we take very seriously, and these long-term relationships are a central legacy of TIES.

Also, our partnership with Dane County has been vital. As the county transitions to the Family Care program, we will need to contract with a managed care organization to continue our services.

There will undoubtedly be changes in the long-term care for individuals with disabilities in our county and state. But we have been preparing to adapt to the coming changes, and we hope to continue to build the relationships and provide the services that we do now for many years to come.

To read the unabridged interview, please visit: waisman.wisc.edu/newsletter.htm

Machine learning can detect a genetic disorder from speech recordings

In a new study, researchers at the Waisman Center and Wisconsin Institute for Discovery have used machine learning to analyze hundreds of voice recordings and accurately identify individuals with a genetic condition known as fragile X premutation, which increases the risk of developing neurodegenerative disorders, infertility or having a child with fragile X syndrome.

While fragile X syndrome — characterized by intellectual disability and behavioral, physical and learning challenges — is relatively rare, millions of people across the world have fragile X premutations.

“But the premutations remain underdiagnosed, and people are often unaware of their increased health risks,” says **Marsha Mailick**, professor of social work and vice chancellor for research and graduate education.

Part of the challenge in diagnosis is that the genetic testing to identify fragile X premutations can be time-consuming and resource-intensive. “We wanted to develop a method to quickly and cost-effectively screen for this condition,” says Mailick.

That led to machine learning — artificial intelligence computer programs that can be “trained” using existing data sets and then used to analyze new information.

“We can go from taking hours to analyze and annotate each recording to needing less than a second,” says **Kris Saha**, assistant professor of biomedical engineering.

The researchers used five-minute recordings of mothers with fragile X premutations talking about their children with fragile X syndrome, and as a comparison, used 100 recordings from mothers of children with autism.

These two groups were chosen because families with children with disabilities often face distinct challenges and stresses compared to families with typically developing children, says **Arezoo Movaghar**, a PhD student at UW-Madison.

Based on transcripts of the recordings, and using

machine learning algorithms, the researchers created a list of language and cognitive features, such as the average length of sentences in the recording or the number of filled pauses — vocalizations, such as “um,” “ah,” or “oh.” They found some of these features more useful in distinguishing between the two groups.

In fact, using the most informative features, the machine learning algorithms could distinguish between mothers with fragile X premutations and mothers without the premutation with 81 percent accuracy.

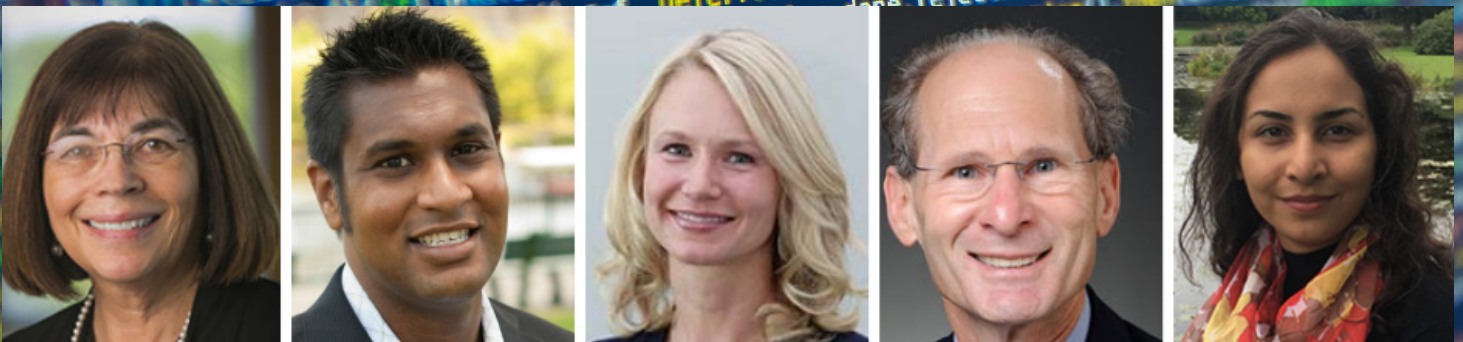
According to calculations by the researchers, machine learning-based screening followed by confirmatory genetic tests would save more than \$11 million compared to using genetic tests alone to identify 1,000 women with fragile X premutations in the general population.

This work is a first step toward a quicker, more cost-effective screening process, says Mailick. “We plan to expand into screening other populations, such as men with fragile X premutations.” And the machine learning algorithms developed in this study don’t have to be limited to health conditions associated with fragile X premutations. “What’s also exciting is the possibility of using similar algorithms for other disorders,” says Saha.

Moving forward, “we want to streamline the way we collect the data,” says Movaghar, who is working to develop a mobile app to accomplish this goal. “It would ask a series of simple personal and medical questions, and then record a five-minute voice sample,” she says. Data could even be sourced from ubiquitous audio recordings on smartphones or smart speakers.

Then the machine learning algorithms would get to work.

To read the unabridged story, please visit waisman.wisc.edu/newsletter.htm



Study authors (from left to right) Marsha Mailick, Kris Saha, Audra Sterling, Jan Greenberg and Arezoo Movaghar

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Monday, July 17

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Waisman Whirl 5k & 10k

Run, Walk & Roll for ALL Abilities

3rd Annual

Sunday, October 15, 10:00 a.m.

Start and finish at the Waisman Center, 1500 Highland Ave



10k Run & Roll

5k Run, Walk & Roll

1 Mile Walk & Roll

Kids' Fun Run & Roll



waisman.wisc.edu/run2017.htm

*Proceeds benefit individuals and families affected by developmental disabilities
and neurodegenerative diseases.*



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Lauren Tierney at the finish line for the 2016 Waisman Whirl, with her brother, Alex, her father, Adam, and her personal care worker, Kathleen (Photo by Niamh Rahman, Waisman Communications)

10-year-old Lauren Tierney had only walked a mile a few times before.

Yet here she was, on a cool October morning, at the starting line for the Waisman Whirl Run Walk & Roll for All Abilities, getting ready to tackle the mile loop. Her bright pink sneakers matched her glasses, her blue walker complemented her teal t-shirt, which proudly proclaimed, “Actually, I can, and I will.”

But would she finish her first official mile walk?

Lauren was born prematurely in March, 2006. She spent the first month and a half in the hospital, where she was diagnosed with cerebral palsy. She has not let her diagnosis slow her down, and she gets around fabulously using her wheelchair, but she has trouble balancing or walking by herself.

“I actually had a big goal of balancing by myself for seven minutes,” says Lauren, “and my OT promised me a cupcake if I could do it.” Some months before the Waisman Whirl, Lauren succeeded in her quest for balance and a cupcake.

Respiratory tests done when Lauren was younger showed that when she

walked using crutches or a walker, she used seven times more energy compared to typically developing children.

Now she uses about four times more energy, which her mother, Sandy Tierney, credits to “good surgery, good PT, good Botox, her pump – Lauren uses a baclofen pump system – and lots of hard work.”

But four times the energy expense meant that a mile walk for Lauren is similar to a four-mile walk for her brother, Alex Tierney.

When Lauren set out on her mile-long Waisman Whirl adventure using her walker, and accompanied by her brother, her father, Adam Tierney, and Kathleen Kubisiak, her personal care and respite worker, she remembers how difficult it was.

“The terrain was really hard,” she says, “and I fell down, twice.” Her father remembers the falls: “You skinned yourself, and you were bleeding a little bit. I wasn’t sure if you were going to finish the walk, because we still had a way to go.”

“I wasn’t sure either,” says Lauren. “I got back up and started crying, but I didn’t want to stop.” She looks at her brother and says, “You helped a lot. I thought, ‘If he can do it, I can too.’”

While cerebral palsy is a big part of her life, “there is a lot more to Lauren,” says her father.

She loves school and learning. “I have been lucky to have some awesome teachers at school, and when I grow up, I want to be a teacher as well,” she says firmly. “I also want to be a self-advocate and teach people about children with special needs.”

She also loves to travel and has gone special-needs skiing in Montana, sailing off of the French coast, free-swimming at a coral reef preserve, and zip-lining in Belize.

Lauren would need all her energy and perseverance to finish the Waisman Whirl. By the time the finish line came into view, she was struggling. “It was really tough,” she says, “but I thought about my shirt and found it helped if I screamed, ‘Actually, I can, and I will!’”

More than one hour and 42 minutes after she set out with her family, respite worker, and walker, Lauren Tierney crossed the finish line.

Registration is now open for the 2017 Waisman Whirl Run, Walk & Roll for All Abilities! To learn more or register for the event, please visit: waisman.wisc.edu/run2017.htm



Art for All

Encompassing a breadth of subject matter and artistic media, the **Harvey A. Stevens International Collection of Art by People with Developmental Disabilities** showcases unique and visually powerful pieces that encourage people of all abilities to express themselves and expand their world through art.

Our recent Call for Art garnered a tremendous response, with more than 75 beautiful submissions from across the US and the world, including the work pictured here!

Michigan Pure Cardinal Red Bird
by Andrew Sloan, an artist from Chicago.