46th Annual Autism Society National Conference Recap

Richard Wolf has been a USA TODAY reporter and editor for more than 25 years, specializing in government and domestic policy. He has covered the Supreme Court since 2012. Prior to that, Mr. Wolf covered the White House, Congress, the federal budget and economics, health care and welfare policy, state and local government, and politics. He served as congressional editor for five years. Before joining USA TODAY in 1987, Mr. Wolf was a Washington correspondent for Gannett News Service and a reporter and editor at Gannett newspapers in New York. He is married with two adult children, one of whom has autism.

What I learned on my summer vacation with the Autism Society:

- Young women with autism can walk across Spain.
- It’s very difficult to high-five a dog.
- Ideally, teaching kids on the spectrum to eat properly should not be done with metal forks.
- Foam battle axes come in very handy when teaching social skills.
- It’s never too late to be diagnosed with autism – even at 65.
- And… There is an endless amount to be inspired by at an Autism Society national conference, if you take the time to learn.

I’m becoming a regular at these events, first as the father of a young adult on the autism spectrum, then as a moderator of sorts, now as a member of the board of directors. But it never gets old.

This year in Denver was a mile-high experience, and I don’t mean because of the pot shops. From Wednesday’s strategic planning session with state and local affiliate leaders to Saturday’s sendoff featuring the incomparable Temple Grandin, the conference offered a vast amount of information that surely sent the 1,000 plus attendees home with new ideas – and, hopefully, renewed optimism.

There’s nothing like this sort of camaraderie to help meet the daily challenges of the autism spectrum. Feeling alone? Frustrated by bureaucracy, trouble at school, transition
to employment? Waiting for what seems like forever for a Medicaid waiver? The annual conference always can help in some way.

It is not the keynote speakers or the 100-plus concurrent sessions over three days that are the most important feature of these confabs (though much more on those later). Instead, it’s the feeling that we’re all in this together, regardless of the role you play — individual on the spectrum, parent, sibling, caregiver, teacher or therapist. It’s the impromptu breakfasts, the “you too?” coffee breaks, the drinks and dinners shared with new comrades-in-arms.

Wednesday of each year’s conference hosts a day-long training session for the over 100 state and local affiliate leaders from across the nation. What an inspiration it was to see so many leaders in the field teaching best practices to each other — and the national staff and board as well! These are the board officers, members, volunteers and paid staffers who are the ground troops of the Autism Society, and they spent all the day learning from each others’ successes in areas ranging from education to advocacy to information & referral.

The conference proper opened with a controversial subject: video games or, specifically, the benefits of game-playing as a way to change the world. Best-selling author Jane McGonigal showed the audience how game-players are at their roots problem-solvers who work collaboratively — one of the many skill sets of gaming that can be leveraged for loftier purposes. Her video presentation was fascinating and it definitely got the juices flowing! Especially from the next speaker, Michelle Garcia Winner, who countered McGonigal’s theory and said people on the spectrum need to get outside and work on their social skills. The two sides made for an intriguing, thought-provoking, out-of-the-box start to Thursday!
The dozens of general sessions that filled the bulk of each day were, for me, the highlight of the conference. I raced from one to the next, gathering bits and pieces of information, inspiration and humor to take back to the larger group each morning. Here’s a sampling from Thursday:

- As Brittany Guarino worked quietly on a Word Search, her father Michael told an amazing story of advocacy for his daughter. Within months of her diagnosis in 1993, he had embarked on a journey that involved every type of therapy available — even swimming with dolphins. (“It was an awesome day,” he said. “She got bit by a jellyfish.”) Brittany now lives in a group home her parents started and has a full life of work, household and farm chores, and fun.

- Marla Souder explained the benefits of animal-assisted therapy with a video in which a dog named Payton patiently offered her hand again and again to a young boy with autism, who did not seem prepared to shake it. Finally, when Payton reached high enough, it became clear the boy wanted to give her a high-five instead. “I have kids who will calm down for Payton, not for me,” Souder said.

- One of my favorite sessions was handled by an adult on the spectrum, Jonathan Dylan Chase of Portland, Ore. After struggling with high-functioning autism through his school years, he now works with young people on social and practical skills rather than the math and reading monotonously drilled into him. Jonathan is a musician — and magician — who learned his considerable social skills through those vocations, not by studying, and he advocates the same for his clients. People can overcome their deficits, he said, “when we help them follow their passion.”

- Amy Gravino’s talk on sex, dating and love was endearing — and at times hilarious. Amy speaks from the heart about her earliest experiences, and she holds nothing back — absolutely nothing. One lesson, she said: never feel shame. “We’re people on the spectrum,” she said. “We have enough to deal with.”

- Barry Prizant’s well-attended session knocked down the notion that autism is a tragedy needing a cure alongside cancer and diabetes. “Doom and Gloom raises money,” he said. Instead, he urged parents and teachers to create positive images, note strengths as well as challenges, and celebrate success.

- Elayne Pearson explained how to get through autism’s emergency meltdowns with natural balms like cleanses and enzymes, mini-trampolines and balance beams, even foot soaks. One lesson: Test them on yourself first. “Everything I did for Heidi, I did it first as her mom,” she said.

- Cathy Purple Cherry, a member of the society’s board of directors, told a similar story, explaining that sometimes you just have to turn off the stage lights aimed at the individual with autism and go take a bath. “I should own stock in ear plugs and bath salts,” she said.
David Geslak celebrated the benefits of exercise in improving behavior and language development – even sleep. “Exercise should be part of their daily routine,” he said. “Try to involve it at an early age if you can.”

In a session on picky eaters, aptly-named Melissa Olive advised: “Prepare for difficult times.” Well, of course – if you are going to change a child’s diet from bacon and potato chips to what she called “real food.” She said that sometimes subtracting sugar, gluten or dairy can seem like heroin withdrawal. “We do it one bite at a time,” she said.

On Friday, those who were awake for the keynote session heard Margaret Bauman and Lucy Jane Miller discuss neuro-physiology and sensory processing – two major issues for individuals on the spectrum and their advocates. This was a more traditional presentation than Thursday’s discussion of video games, enlivened in particular by Dr. Bauman’s use of humor to make a difficult subject easier to understand.

The day’s general sessions were inspirational, illuminating, wonderfully touching, and often hilarious. Parents were advised to be pests: “The reason why all of us are here today is not because of reasonable parents – it’s because of unreasonable parents.” Brothers and sisters were reminded of their lifelong role: “Siblings are the longest relationship you’re going to have in your life.” And we were scolded by a self-advocate who found his audience to be too well-behaved: “Folks, you’re at an autism conference — act like you belong here!”

That last piece of wisdom came from Jeff Newman, who said it’s important to acknowledge who you are, because if not, “Every day is failure, every day is isolation.”
“We no longer feel obligated to be like everyone else,” Newman said. “We will stop teaching you that normal is good and different is bad…. We will stop using terms like ‘suffering from.’”

Every year, the session featuring siblings is, for me, the most touching. This year, if featured two sisters of people on the spectrum and a pair of brothers, one of whom is on it.

They talked about how close they all are now with their siblings, how the relationships have made them more mature and compassionate, and how they could not imagine living the rest of their lives without their sisters or brothers on the spectrum. Sandra Tucker said sisters “instantly take on that caregiver role.” Melissa Olive, whose brother has autism, said she cannot envision a future “without having him in it.” And Jason Cherry said he and his other siblings will stay very tight with brother Matthew -- “as long as he doesn’t jump out any more windows.”

In a session entitled “Speaking Geek,” Jennifer O’Toole explained that people like herself on the spectrum often go too fast from catalyst to response and miss “the moment where emotional intelligence makes all the difference.” Films like the animated “It’s All Right” starring Amy Poehler, she said, can help to show how emotions such as anger, fear, joy and sadness play a role in our lives.

Yael Calhoun said simple exercises such as yoga can help with what she called “compassion fatigue.” Yoga helps clients live in the moment, also called “being present.” Meditation also is beneficial. “If you’re not paying attention, you’re not rewiring the brain,” she said.

In a session that warned “A friend is not always a friend,” Barbara Klipper walked parents through the dangers of being online. There are lots of things to avoid in cyberspace – flirting that borders on stalking, posts that can make you vulnerable to crime, scams, cyber-bullying and, of course, illegal behavior. “The courts,” she said, “do not take autism as an excuse to get you out of things.”

David Finch, a popular writer and humorist, said schools need to do a better job of preparing students on the spectrum for the real world they often don’t understand. What’s important, he said, are the challenges that lie ahead – perhaps college, applying for and keeping jobs, getting married, even having families. “We’re not educating kids on how to make those emotional, awesome connections,” he said.

Jack Scott presented two great sessions about keeping individuals on the spectrum safe. He addressed the problems of elopement and wandering. Electronic tracking devices, usually worn on a wrist, are an excellent way for police to be able to find individuals who go missing, he said. He also recommended entering the person’s emergency contact form in the 911 system.

Kate Palmer talked about the benefits of self-employment and named some of the top companies employing people on the spectrum, such as Walgreens and Home Depot. She said job coaches are key; she offered practical advice
on dealing with bosses, co-workers and clients; and she said while disclosing your disability isn’t necessary, it usually is beneficial. “If you ask for reasonable accommodations, your employer has to give it to you,” she said. “But you have to ask.”

David Holmes, who always has great practical advice for negotiating the labyrinthine bureaucracies that we all face, walked us through Medicaid, the IDEA law, health insurance and Social Security. “Social Security likes to get to ‘no,’” he said. “Not ‘know,’ but ‘no.’” He also said IEPs inevitably are geared more toward the school’s needs than the student’s. “I haven’t seen an IEP that I haven’t been able to tear apart,” he said.

As mentioned, Saturday’s wrap-up keynote address on exceptional individuals on the spectrum featured Temple Grandin in her home state, along with Diane Kennedy, Rebecca Banks, Jennifer O’Toole and Patricia Gatto-Walden. These gifted women completed a trifecta for the keynote sessions – every presenter was female. Perhaps as a result, the information and advice they offered was of the practical, no-nonsense variety. As we know, Temple doesn’t mince words!

The conference was rounded out by more than fifty exhibitors demonstrating and selling everything from books, videos and software to snug vests and sand timers. Each morning and throughout the days, those in attendance took full advantage of the breaks between sessions to grab a cup of coffee and stroll through the rows of colorful booths. One morning, those in attendance were able to snap selfies with none other than Grover of Sesame Street, on hand to announce a new collaboration with the Autism Society.

And no summary of conference events would be complete without a shout-out to the award winners – Ann Hart, Tracy White, Sharon Francis, Melissa Burkhardt, John Miller, Oliver Wendt, the Autistic Global Initiative, Johnny Carino’s Italian Restaurants, the Autism Society Heartland, and especially young Conner Cummings from my home area of Northern Virginia, who brought the house down with a wonderful speech after being named Outstanding Advocate of the Year. Well done, Conner!!

The Autism Society of Colorado deserves mucho applause for putting on a great show in Denver on our 50th anniversary. Now it’s on to the next 50 – starting next year in New Orleans! If you haven’t attended a national conference before, what better locale than Bourbon Street to sample your first? You won’t regret it.