



AutCom Conference 2021 Goes Online, Still October 15-16

Our plans have changed! We recognize that with ongoing concerns about the pandemic, many people will not be comfortable traveling this fall, so it seems sensible to hold a virtual conference this year and to plan for an in-person conference in 2023.

Planning is underway for a two-day conference online. One day will focus on issues relating to employment and autism. The other day will focus on law enforcement and autism issues and concerns. Each day there will be a keynote presentation in late morning and a panel in early afternoon (Eastern Time). We will release information on our website and Facebook page about presenters and registration once everything is in place. We hope that you will join us!

AutCom Is Seeking Additional Board Members

We are recruiting additional Board members to strengthen AutCom and to help us move boldly together into the future. The Principles of the Autism National Committee on page 19 of this newsletter explains our values. If you share our values and have time and energy to dedicate to monthly or bi-monthly meetings, committee work, social media, writing, planning, or other tasks, we want to hear from you. We are especially looking for someone with skills in website maintenance. Please provide a brief biography and let us know how you would like to contribute as a Board Member to the future of AutCom. Help us to become a more diverse and vibrant organization, and work with us to increase our efforts to build a better world for all.

Join us on Facebook! "Like" and share all our perspectives far and wide.

<https://www.facebook.com/autcom>



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Renew Your Membership!
(See the form on page 20.)

Invitation to AutCom Annual Meeting

The AutCom Annual Meeting will be held by Zoom on Sunday, December 5, 2021, at 4:00 pm EST.

- If you would like to attend, email info@autcom.org
- In the Subject, write "Attend Annual Meeting" and a Zoom link will be sent to you.

Having Autism by Meagan Buckley

Having autism is not something you choose. It is something that gets brought to you, kind of like a lousy gift. At first it can be awful because the sensory distortions are truly frightening, but as you grow older and become more accustomed to them, you figure out ways to cope. You have to, or you would curl up in a ball and stay that way forever. Having autism is hard work. It feels like I am having a meltdown all the time. I am always on hyper drive. At first, I thought I was crazy. Then I realized that I was just different. And I am OK with that.

What people don't understand is that everyone finds their own way of existing in the world. For some of us, that existence is made more difficult by preconceptions that are false. For a long time, too many of us were unable to refute these beliefs, but now I can communicate by typing.

You see, I have always had words inside my head. Piles and piles of words. The problem is, I cannot speak these words because my nervous system is too hyped up, and my motor impulses are hard to control. I struggle mightily every minute of every day to control my impulsivity. The hardest thing I have ever done is learn to type without support, but it is also the most important thing.

This might not seem like a big deal to you, but when I discovered that my finger could do the talking, it was the very best day of my life. For almost 30 years, all my words and thoughts were trapped inside my head, and suddenly they were being set free. For me, typing is a natural means of expression, kind of like your voice is for you.

I have goals in my life just like everyone else. An important one is to teach others about autism. Understanding is the key to getting better services and results. I want to spread the word that autism is not something to fear, but rather something to have respect for. Those of us with

autism are not crippled, but rather blessed with having heightened sensitivities and abilities. Not being able to communicate this to those who so misjudge us is the ultimate irony and tragedy.

Excerpt from The Meaghan Report

<https://tinyurl.com/3u5skdpp>



Meagan Buckley

Meaghan Buckley is a 36 year old autistic writer. She is the role model for the character Anna in her upcoming book, *Who Is Anna*, which she co-wrote with her mother, Gail. Meaghan's family did not discover her remarkable intelligence and ability to express her thoughts through typing until she was 29 years old. She has given presentations at several local colleges, Boston University and Leslie College and at the 2019 AutCom Conference. Meaghan lived at home, attending Boston Higashi School, until she turned 21. She now lives in a home with four other autistics.

Life As I Know it

by Anthony Brown



Anthony Brown

Interconnected so it seems
Roaming galaxies in our dreams
Hearing the frequency
Feeling the sound
Love come to greet us
Pulsing all around
Joining with friends in this space
Replenishes my soul
Filling it up with grace
Joyous rapture is what I feel
Ready to strive to give one more appeal
Grasping at stars willing to see
There is so much to life
So much to conceive

Biography

I am a nonverbal man. I am twenty eight years old. My poems were written using supported typing. Some of the time, I had support. Other times I typed as my partner held the keyboard. My interest is in educating others about partnered communication .

In Memoriam: Dave Hingsburger

Dave Hingsburger has been a giant in the field of developmental disabilities. As a clinician, trainer and author, Dave has been a tireless advocate for the rights and freedom for people with developmental disabilities. He has authored several books that have been used by generations of disability professionals across the world to help them understand issues of humanity. He was also the founder and editor of the *International Journal for Direct Support Professionals*, a set of easy to-read, practical articles on a variety of topics that are pertinent to their role in supporting people with developmental disabilities. In Dave's many books and presentations, his humor, humanity, and trust in people to make good decisions for themselves shone through. We will miss you, Dave, but the important lessons you have taught us remain.

The Game Changer

by Will Fried

I was 14 years old and always enjoyed being around the game of basketball. I had so much fun playing on a recreational team but always wanted to play on a more competitive basketball team. I had the ambition to keep on trying after being cut from every basketball team that I tried out for in the years of 2009, 2010, 2011, 2012. It was finally in 2013 that Coach Feldman gave me a chance to play on a 16U basketball team for the next two years in 2013 and 2014.

When I got to play on this team, I had so much fun because I finally got to play for a coach who trusted me to be on the court. I was appreciated on this team from the moment I stepped on the court, even though I was the last player off the bench in both years. I was not sorry for myself at all, and I gave it my all with enthusiasm. The rest of the team appreciated that and cheered for me from the first basket I made on this team. These teammates treated me extra special. In my final game with this team, I played my heart out even when we were losing because I loved them so much. I could not wait to come back for one more season.

After year one on this team was finished, I was a few days later working on getting my basketball skills better. In the off season, I worked on being a better scorer from the three-point line because that was needed on this team for my second season. I showed up to the first practice of the second session with a mentality to work harder and get better. From this first practice, my teammates were happy to be back with me.

This second and final season gave me lots of memories and a close bond with my teammates. We doubled the number of games we won because of our tight bond and made it to the championship game with me even contributing. In the championship game, I helped the team gain a lead by scoring back to back buckets while being on the autism spectrum. My teammates were screaming for me and proud of me. The other team had no scouting report on me because I was a player who did not play much or score many points at all. After this game, I knew I wanted to



Will Fried, on the left, is pictured with basketball officiating friend Nathan Loibl at Court Club Elite basketball officiating camp, one of the top such camps in the country.

stay around the game of basketball because this coach transformed my life into myself being a leader. I asked the coach that evening, next year can I please help you coach the basketball team? He responded with, "Yes!"

The next year, I became a coach for this team, and I dreamed so much of being one. During my first year, I helped run tryouts and practices. I was even allowed to evaluate players and help make roster decisions. I just remember my first time coaching, I really enjoyed seeing the excitement of the players who wanted to be there and appreciated me coaching with a disability. I spent time coaching this team for two years and helped make a difference in their lives. I really appreciated what Coach Feldman did to give me the opportunity. After my second season coaching this team, I got the opportunity to start working as a Camp Coach at Coach Wooten's Basketball Camp, which was a dream come true. This would have not happened for me unless Coach Feldman helped me become a basketball coach.

At Coach Wootten's Basketball Camp, I got to learn from so many experienced basketball coaches and got to become a better coach overall. I did whatever it took to get better, which meant getting up at 5:30 am to coach campers in the early bird stations as well as staying later at 9 pm to work the late night basketball stations with other coaches. I wanted to do whatever I could to get better. Doing all the extra work helped me establish connections in the Basketball Coaching Ranks for the rest of my life.

If you want something so badly, you have to tough it out with grit, passion and always have the eye of the tiger because your players look up to you as a leader.

My Favorite Days at Camp

by Jared Don

For the most part, I have the goal of moving and sitting outside at the end of summer. The thing that I face in the toll that is happening this year with coronavirus is that I haven't gone to summer camp. I went the year before and got wistful thinking about camp. My favorite days were at camp as long as I could keep my OCD (sensory interests and repetitive movements) in control. The activities at camp were so much fun, and I have good memories about the folks that were interested in me. The very single thing that made my day happy was how well I stayed in the best state of mind. The activities were definitely important to keep the compulsions from controlling the day. Overcoming the OCD was my biggest challenge at camp.

In the mornings, we sometimes had Zam dance with everyone together in a tent. I was not thrilled about going because I thought of myself as a bad dancer. However, I was willing to force myself to try. I liked being with the group and the music made me feel happy. My counselor said, "Do what I do," and she helped me learn the steps. I started to have fun even though it was hard to have the right moves. The movement helped me think in the present and be with the group.

My favorite part of the day was going to the pool. I love the feel of the water and sun on my body. When I swim, I focus on the feeling of going

Brief biography of Will Fried

Will Fried is a full-time student at Fort Hays State University, in Hays, Kansas, in the Higher Education and Student Affairs Master's Program, as well as a Fulbright Alternate to Finland. In May 2020, he graduated from Salisbury University Magna Cum Laude with a Bachelor's Degree in Conflict Analysis and Dispute Resolution Interpersonal Track and was awarded the A.K Talbot Award for his commitment to civil rights and community advocacy. Will Fried presents and gives talks around the country about disability advocacy, transition for high school students with disabilities, transformational leaders, and athletic coaching.



Jared Don

through the water. The force of the water when I swim regulates me. I had fun with the others when we went underwater. I get a charge out of floating on my back to rest. I also got very good at tolerating the slide, although it's not the best part for me. After I swim, I feel calm, have better ability to follow directions, and sleep the whole night through.

Another great thing at camp were the trips. I liked traveling on the bus. When I ride the bus, I like to look out the window and think about what I will do in the future. One wonderful trip at camp was doing horticulture at a farm. I found that the physical labor was helpful to my state of body control. Another trip was to a museum where we

did an art project. We also went on a boat ride and to a water park. The water park was the activity that most took me to a state for a calm body.

The activities at camp were what had the most help for me to control my OCD. The challenge was still there, however, during transitions: getting out

of the pool, getting off the bus, and between one activity to the next. If I can do the forced interest in the behavior that is socially acceptable, I hope to be able to go to camp this summer to have more of my favorite days.

Tiffany Broskoskie

My name is Tiffany Broskoskie. I am 19 years old with Autism Spectrum Disorder. I live in Kenilworth, NJ, and I found my voice of writing through Rapid Prompt Method and my magical thoughts to my poems come through my ability to see things in a more beautiful, natural form of life. I love to write my words in a more creative way and to let my readers enjoy my poems from my words that come from my loving heart.

When Sand Meets Feet

Course grains of sand stick to bare feet along an eroded path to the foam of crashing waves.

Crystal blue-green water seamlessly blends into multishaded brown sand on a picturesque beach made for walking along step after step.

Lovely waves smell of sand with every churn the vast ocean brings in rotation.

My eager nose widens and breathes in the salty therapeutic air.

Waves subtly move back and forth while my tired ears tune into the light whisper noise that soothes my mind.

Pungent salt fills my tongue and taste buds and the taste engulfs my dry mouth like a snake devouring its prey.

When untouched sand meets feet, my heavy head feels uncluttered and drowsy body at ease.

I would rather be than at the beach.



Tiffany Broskoskie

Down the Shore

I am in heaven when I'm at the beach.

I am in love with the crystal clear waves hitting the shore

Over and over again like an ever beating drum.

I am in my happy place listening to the ocean softly flow

Like ice cream soda into an icy glass.

I am in a dream with the blissful feeling of the delicate

Sand moving in between my fingers and toes like an hourglass.

I am in a light blanket of sand at every turn.

I am in a fairy tale where the salty aroma in my nose

Captivates my attention like Prince Charming seeing

Cinderella for the very first time.

I am in a fantasy land where there is no other place



Autism Sibs - Meghana & Chetan Junnuru

We go by the brand name 'Autism Sibs' and maintain a blog site (www.growourjoy.org) to express our joy for writing. Our goal is to share our story, our inner thoughts and progress with as wide an audience as possible. Here is one of our poems.

Finding Our Destiny in Life

Our life like a divine
 natural maze
 finds us laughing
 as we oscillate our centers
 between the full spectrum
 of autism and neurodiversity
 trying to find our destiny in life

We strongly emphasize
 that we are writing
 from our hearts
 and from a deep analysis
 and experience
 of how autistic bodies
 and brains function

Beyond our external façade
 throbs innovative and intricate
 fire inside us
 to create our future while
 serving others with autism

Benign in how we see the world
 our guidance will create
 a very gentle and compassionate
 person-centered non-profit
 autism center developed by Autistics

The center's approach will positively
 alter the lives of Autistics
 otherwise trapped in systems
 that are unable to fully serve them
 primarily from a lack of
 true understanding of autism

Thoughts are Powerful

by Jack Mason

I am Jack Mason. I am autistic and have trouble saying my words. I often do things that are at odds with my brain. For example, I go to say “I want some coffee” but it comes out as “I want to buy a soda.”

I think it is because I can't control my movements or feel my body in space. This is very frustrating to me. Even now as I am typing this, my mouth is running on about stupid things. The things I am saying distract me; however, I have no control over them.

MY CHILDHOOD

I was born in Massachusetts in 1984. My first memory is going to the Topsfield fair with my parents. I saw animals and carnival rides at the fair. I was two years old. How was I supposed to know that it would be my last carefree time before autism destroyed my life? I lost my ability to speak what I truly thought and felt. My parents were frustrated that I could not really respond to them the way I used to. I could not control my body and began doing crazy things like running away from my mom in the park. I brought my stuffed lamb where people did not want it. There were so many times I wanted to tell my parents how kind they were, but my words came out [as] questions about people's names or other nonsense. By the age of sixteen, my speech consisted of failed phrases.

MY DIAGNOSIS

I was four when my parents took me to a blood specialist, who said that I was either retarded or autistic. My parents were devastated and disappointed. They wanted a normal son but got me instead. I felt that I was trapped in my body with no way out. Rather than have me learn like other kids, I was another case of a special needs child shunted off to a school where my gifts were covered over. I was able to reason my worse days by reading every part of the Boston Globe sports section and the dictionary.

Having two lawyers for parents was the

advantage I needed to survive. They protected me from the abysmal reach of institutes practicing behavior modification.

I thought that I would love going to school because I wanted to get an education, but my teachers educated me by having me do the same things rotely year in and year out. I had to practice talking about the date and the weather daily instead of learning about history, science and math. They assumed that I could not be taught because I could not control my speech and my body. I was really frustrated and developed worse behavior. This made my teachers assume that they were right about me, so they kept denying me my rightful education.

WEIRD THINGS START TO HAPPEN

Crises occur on a regular basis when you have autism. If your body does not respond to your brain, your body effectively belongs to a stranger. For example, I want to tell my staff that I am thirsty, but it comes out as I need to go to [the] restroom. Or I am tired, but my body will go take a walk. This is very frustrating for me. I get very anxious and start asking stupid questions like what is your name and are we going to Wendy's? Your attitude toward me reflects your belief that I have nothing worthwhile to say.

TRYING TO CONTROL MY BODY

My parents tried every technique under the sun to get me to talk normally. They took me to ear training, neurofeedback, behavior modification. Nothing helped me except that my hearing became less sensitive. Hardest of all was behavior modification because I was treated like a dog. They would teach me to comply and reward me with edibles. It was humiliating.

FINDING MY VOICE

Nobody understood me; however there is somebody who found me. She introduced me to typing. She ignored the autistic behavior and focused on getting my eyes and one finger to

connect with the alphabet. I got to type real thoughts and ideas instead of the asinine garbage that usually came out of my mouth. It took years to reach the point that I could type with her hand on my back.

My first attempts at typing were disastrous. I thought that Lisa was trying to do the impossible by making me stop talking and start typing. I finally figured out that typing does not restrict your voice, it magnifies it by allowing your body to listen to your brain. Forcing me to act like a normal person has been the hardest thing for me to learn.

There were times I thought my body would never obey my brain and I despaired of ever breaking free. There is a wealth of knowledge about motor planning and autism, but the ones in

control try to take the motor pieces away. I really think that thoughts are powerful and there are many ways to exercise your speech.

MY NEXT MOVES

How does this get me to a place where I could advocate for myself? Will anyone believe that it is really me typing, or will they express disbelief because someone is physically supporting me? I want to study for my degree and have a career as a lawyer because I admire my old man. I want to talk like other people. I want to be in a relationship. Having some kind people at Communitas (my day program) is okay, but there is a whole other world out there. I want to see it.

Legislative and Policy Issues Update

by Alan Kurtz

First, the good news! Thanks to the advocacy of many organizations, the latest COVID-19 relief bill, *the American Rescue Plan Act*, contains dedicated funding for Home and Community-Based Services (HCBS). HCBS funding is vital for many autistics, as well as other disabled individuals, who receive support to live in the community rather than in institutional settings. It remains important for members of this and other advocacy organizations to monitor how your state is using these funds and to ensure that Medicaid-funded services are person-centered and provided by highly qualified providers in truly inclusive settings.

Keeping All Students Safe Act

This act would prohibit seclusion, mechanical restraints, chemical restraints, and physical restraint that restricts breathing or is life threatening including prone and supine restraint. It would also prohibit physical restraint as a planned intervention and require parental notification and follow-up meetings if a physical restraint occurs. This legislation is vital for protecting students from practices that have proven to be both incredibly traumatic and, in many cases, deadly. Our friends at the Autistic Self-Advocacy Network (ASAN) have issued an action alert on this legislation

and recommend the following language when contacting your Representative or Senator:

My name is [your full name], and I am from [city]. I'm [calling/writing] to ask the [Senator/ Representative] to support the Keeping All Students Safe Act. This bill would ban restraint and seclusion, two life-threatening practices that disproportionately impact students with disabilities and students of color. Ending the use of restraint and seclusion would save lives, prevent abuse, and make our schools safer and more equitable. Can I count on you to work to pass the Keeping All Students Safe Act?

The Better Care Better Jobs Act

The Biden Administration has proposed a \$400 billion dollar investment in the HCBS system as part of his proposed American Jobs Plan. It is vital that advocates and self-advocates let their Congressional Representatives and Senators know how important this funding is to the lives of autistic people (and all people with disabilities) and those who care about them. Democrats are trying to pass this bill through the Budget Reconciliation process – a process that will require all 50 Democratic and Independent Senators.

There are some steps you can take to make sure it is enacted. First, if you have a Democratic Senator, find out if they have co-sponsored this legislation. If they have, thank them and stress how important this legislation is. If they have not, reach out to them and share why this legislation is important and ask them if they would consider co-sponsorship. The reconciliation process will require all 50 Democrats and Independents to support it. If you have a Republican Senator, reach out to them and share why you believe HCBS is important.

Money Follows the Person

The Money Follows the Person Act (MPF) was extended for three years through the Budget Consolidation Act in December of 2020. MPF has been incredibly valuable in helping many disabled individuals and seniors move from institutions and nursing homes to their community. Unfortunately, the lack of permanent funding has led many states to reduce the number of transitions to the community through this program. Congress considered a bill in 2019, the Prescription Price Reduction Act, that was supported by both major parties. This was put on hold, however, due to Covid-19. Your representatives and senators need to hear about how important MPF is and how it can improve the quality of life of countless autistic and other disabled individuals.

The Transformation to Competitive Employment Act

This bi-partisan Act was introduced in 2019 and would

- Phase out 14(c) certificates and end subminimum wage over six years;
- Create a competitive grant program that

would be used to help 14(c) holders convert to models supporting competitive and integrated employment; and

- Establish a Technical Assistance Center to support the transition to competitive, integrated employment.

Essentially, the purpose of this bill is to end the practice of segregating disabled individuals in settings where they are usually paid far below minimum wage, while supporting the transition to productive work for reasonable pay in integrated settings. This bill is currently being reviewed by the US Senate Committee on Health, Education, Labor and Pensions.

Sadly, One Giant Step Backwards

Last year, the FDA finally issued regulations that would ban the use of skin shock device, the graduated electronic decelerator (GED), for use on disabled people. This was great news for all those who had fought tirelessly for years to end this barbaric practice. In response, the only institution in the US using these devices, the Judge Rotenberg Center (JRC) in Massachusetts, filed a lawsuit against the FDA. On July 7th, the DC District Court ruled that JRC could continue using electric shock to control the behavior of its students. The court did not rule about whether the FDA could ban a device, but instead “that the FDA lacks the statutory authority to ban a medical device for a particular use.” This is horrible news for those of us who have been fighting against the use of this torture for many years. So the battle continues. We need to continue to advocate with our elected representatives, the FDA, and in the courts to eliminate this horrible practice.



Time to Renew or Join Today!

Annual membership begins in January

Membership form on page 20.



Bills in Congress to Address Law Enforcement and Persons with Disabilities

by Joanne Cafiero

Two new bills are up for a vote in Congress that are relevant to all of us. Please refer to the links below for more detailed information.

The Human-Services Emergency Logistics Program (HELP) Act.

The Human-Services Emergency Logistics Program or the HELP Act is a bill in Congress designed to address the vulnerable and disabled American citizens who account for up to 25%-50% of all police shootings in the United States. This bill provides the infrastructure through a 211 phone line, rather than a 911 line, that will send trained mental health and human service providers and professionals to crisis situations rather than law enforcement. This bill would divert non-criminal, non-medical, non-fire emergencies from State 911 to 211 systems and would include the funding to link callers not only to emergency services but to robust, long-term support services. This bill would include an oversight system comprised of community members who represent adults, people with disabilities, and racial and ethnic community members.

The HELP Act is supported by United Way Worldwide, National Council on Independent Living, Bazelon Center for Mental Health Law, National Alliance to End Homelessness, The ARC of the United States, National Association for the Deaf, National Down Syndrome Congress, Association of University Centers on Disabilities, Paralyzed Veterans of American, Public Interest Law Center, and the Center for American Progress. It is sponsored by Senator Bob Casey and co-sponsored by Senators Gillibrand, Duckworth, Merkley, Hirono, Brown, Blumenthal and Baldwin.

Summary of the HELP Act:

Please call your members in Congress and the sponsors of this bill to voice your support. (202-224-3121).

<https://tinyurl.com/2wn3d23p>

The Safe Interactions Act (SIA)

The Safe Interactions Act is a bill that will address the tragic fact that people with disabilities comprise between 1/3 to 1/2 of all individuals shot by law enforcement officers. This highlights the dire need for increased and ongoing training to protect both law enforcement and the communities they serve.

This bill provides grants to enable non-profit disability organizations who have formed a partnership with a law enforcement agency to develop programs that support safe interactions between law enforcement officers and people with disabilities by increasing the levels of understanding concerning different disability types among new and veteran law enforcement. It will promote partnerships between law enforcement and non-profit disability organizations that address intellectual and developmental disabilities, mental health, sensory and /or physical disabilities. Training content and protocols will be developed by a team of diverse self-advocates representing a variety of disabilities.

This bill is currently supported by Autism Society of America, ARC of the United States, National Disability Rights Network, Autism Connection of PA, National Association of the Deaf, Association of University Centers on Disabilities, Public Interest Law Center, and Center for American Progress. It is sponsored by U.S. Senator Bob Casey and co-sponsored by Senators Gillibrand, Duckworth, Merkley, Hirono, Blumenthal, and Brown.

Summary of the Safe Interactions Act:

Please call your members in Congress and the sponsors of this bill to voice your support. (202-224-3121).

<https://tinyurl.com/4zftawd>

Wait!

Didn't the FDA End the Use of Electric Shock at the Judge Rotenberg Center??

by Nancy Weiss

Just over a year ago, advocates celebrated the FDA's decision to ban the use of electrical stimulation devices for self-injurious or aggressive behavior. Advocates had been working for years toward this goal. On March 4, 2020, the FDA announced this ban because they determined that these devices presented "unreasonable and substantial risk of illness or injury." While this decision wasn't aimed specifically at the Judge Rotenberg Center in Canton, Massachusetts, it is the only known facility in the U.S. or worldwide that uses electric shock as punishment. At the Judge Rotenberg Center (JRC), residents wear backpacks containing electric shock devices. Horrifically painful shocks are delivered for behaviors that the facility deems inappropriate. This severe punishment can be applied even for completely innocuous behaviors like taking one's eyes off of their work, failing to maintain a neat appearance, stopping work for more than a few seconds, whispering, making more than five noises in an hour, or having a toileting accident.

In announcing the ban, the FDA published a press release in which William Maisel, M.D., the Director of the Office of Product Evaluation and Quality in the FDA's Center for Devices and Radiological Health, said, "Since electrical stimulation devices were first marketed more than 20 years ago, we have gained a better understanding of the danger these devices present to public health. Through advancements in medical science, there are now more treatment options available to reduce or stop self-injurious or aggressive behavior, thus avoiding the substantial risk electrical stimulation devices present." The ban was to be effective on April 6, 2020, just over a month after it was announced, however, for those people on whom electric shock devices were currently in use, the FDA provided an extension of the effective date. In recognition of the need for a transition plan, for people on whom

devices were currently in use, the date by which the use of electric shock as punishment needed to be discontinued was extended to September 2, 2020.

On March 27, 2020, just a few days after the ban was announced, JRC filed a motion for an administrative stay with the United States Court of Appeals. The motion requested that the courts delay any ban of the devices until all legal challenges to the ban were resolved, including an appeal of the FDA's decision that JRC intended to file. JRC additionally requested that the FDA delay the ban of the devices because of the pandemic which had only recently become a national emergency. JRC said that a delay of the ban was needed because medical doctors were necessary to develop transition plans for the JRC residents currently subjected to electric shock. As well, they said that a delay was needed because the attention of medical doctors was now focused on the pandemic; therefore, it would not be possible for JRC to discontinue use of the devices.

On the same day that JRC filed the motion to delay any action toward banning the devices, the FDA agreed to a 'limited stay.' They explained that their decision to grant the stay (or delay) was made: in light of the pandemic; in consideration of the fact that people were advised to limit contact with healthcare providers; because they acknowledged that the creation or implementation of physician-directed transition plans had the potential to increase the risk of transmission or exposure to the virus, and because healthcare resources may be diverted elsewhere during the pandemic.

The FDA's letter to JRC said that it "finds that it is in the public interest and interest of justice" to grant a limited stay which was "intended to remain in effect for the duration of the public health emergency related to COVID-19 declared by HHS." Their response said further that once

the public health emergency ended, and while JRC's legal challenge to the ban was pending, the stay (or delay of any action toward the ban) would remain in effect. The FDA's response meant that shock devices could continue to be used at JRC until both the pandemic is no longer a national emergency *and* all legal challenges to the FDA's ban were resolved.

As expected, JRC filed a Petition for Review of a Final Rule of the FDA on November 16, 2020. Their 63-page brief challenged both the FDA's decision to ban the devices and their right to make a decision of this nature. The U.S. Department of Justice filed a brief on behalf of the FDA (that is in support of the decision to ban the devices) on January 15, 2021 and a number of disability groups (see list below*) filed a brief on January 22nd urging that the ban of these devices go into effect.

So, did the FDA pass regulations that protect people from electric shock used to punish people's behavior?

Yes – but tragically, the ban is not in effect currently and there's no telling when these protections will actually be enacted.

*The January 22nd brief in support of the ban on electric shock devices used for behavior control was filed on behalf of American Academy of Pediatrics, American Association on Intellectual and Developmental Disabilities, American Academy of Developmental Medicine and Dentistry, International Association for the Scientific Study of Intellectual and Developmental Disabilities, National Association of State Directors of Developmental Disabilities Services, National Association of State Directors of Special Education, and National Association of the Dually Diagnosed.

Note: This report is from March, 2021. See a brief update on the latest development in the fight to ban the use of electric skin shock for behavioral control in Legislative and Policy Issues Update by Alan Kurtz elsewhere in this issue.

Nancy Weiss, Director, National Leadership Consortium on Developmental Disabilities, University of Delaware
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AutCom Opposes the BIG Act!

AutCom joins the Coalition for Smart Safety and allies, including Autistic Self Advocacy Network, National Disability Rights Network, Council of Parent Attorneys and Advocates and others, in opposing the Behavioral Intervention Guidelines Act (BIG Act). Earlier this year, the Coalition sent a letter to leaders in the Senate expressing major concerns with the bill. Here is an excerpt.

“The Coalition for Smart Safety and allies include disability rights, civil rights, education, privacy, and faith organizations [who are] working together to stop the false association of gun violence and violence generally with psychiatric disability. We oppose this legislation's promotion of the use of threat assessments, violence risk assessments, and the preemptive use of law enforcement, including School Resource Officers, to address student behaviors that are deemed problematic. Collectively, these measures do

little more than harden schools and put the well-being of students, especially students of color and students with disabilities, at risk of further marginalization and in some cases serious physical injury or even death.

We are fundamentally opposed to the notion that behavioral interventions in schools begin with the assumption that the student is a threat and that a threat must be mitigated. Students of color are over-policed and disproportionately disciplined in schools and we should curb this problem rather than further entrenching ineffective and discriminatory systems such as violence risk assessments and police in schools. Threat assessments have similarly swept in disproportionate numbers of children of color and children with disabilities. Additionally, the bill does not address how it would interact with students covered under the Individuals with Disabilities Education Act

and Section 504 of the Rehabilitation Act which is of great concern, particularly since threat assessments have frequently resulted in children being removed from school for prolonged periods of time due to disability-related behaviors that could and should be addressed through special education and other school-based services.”

We encourage you to learn about the BIG Act and the serious concerns we have about it. We hope that you will contact your Senator to express your concerns. The entire letter is available at this link.

<https://tinyurl.com/4jt4dr4a>

New and Exciting

The Autistic People of Color Fund provides small microgrants to autistic PoC (People of Color) to meet important needs.

<https://awnnetwork.org/apoc/>

Congratulations to Will Fried, autistic college graduate and advocate. His alma mater, Salisbury University, established the Will Fried Outstanding Undergraduate Student Advocate Award to honor his four years of groundbreaking disability advocacy work while he was a student there. Fried is now at Fort Hays State University working on a master's degree in Higher Education and Student Affairs.

<https://youtu.be/7IAWMpjSRBo>

The Ed Wiley Autism Acceptance Lending Library website now includes Neurodiversity 101, a series of informative graphics with accompanying image descriptions, featuring their neurodivergent narwhal characters.

<https://tinyurl.com/hb9whzaz>

International Association for Spelling to Communicate (I-ASC) presents the Neurolyrical Café, an online series of open mic nights with music and poetry, supporting and promoting the global voices of people who use multimodal means of communication.

<https://i-asc.org/neurolyricalcafe/>

Books and Other Publications

The Autistic Trans Guide to Life by Yenn Purkis and Wenn B. Lawson

<https://www.bookdepository.com/Autistic-Trans-Guide-Life-Yenn-Purkis/9781787753914>

The Many Mysteries of the Finkel Family by autistic author Sarah Kapit - about a family with two adolescent autistic sisters, one of whom uses a tablet to communicate

<https://tinyurl.com/4f8txp4h>

A Neurodiverse View of the World: My Poetry Anthology by Darren W. Stella, illustrations by Jade Z. Stella

<https://tinyurl.com/kpv67t5j>

“Neurodiversity in Relation: Artistic Intraethnographic Practice” by Estée Klar and Adam Wolfond, in the book *Centering Diverse Bodyminds in Critical Qualitative Inquiry*, edited by Emily A. Nusbaum and Jessica Nina Lester

<https://www.routledge.com/Centering-Diverse-Bodyminds-in-Critical-Qualitative-Inquiry/Lester-Nusbaum/p/book/9780367470869>

The Secret Life of Rose: Inside An Autistic Head by Rose Smitten and Jodie Smitten

<https://tinyurl.com/vc554mdy>

Sincerely, Your Autistic Child: What People on the Autism Spectrum Wish Their Parents Knew about Growing Up, Acceptance, and Identity by Autistic Women and Nonbinary Network. Edited by Emily Paige Ballou, Sharon daVanport and Morénike Giwa Onaiwu.

Updated and expanded re-publication featuring new chapters by Lydia X.Z. Brown, Amethyst Schaber, Kayla Rodriguez, Mallory Cruz, Kayla Smith, Morénike Giwa Onaiwu, and Victoria M. Rodríguez-Roldán

<https://tinyurl.com/mt56r735>

Start Here: A Guide for Parents of Autistic Kids - a booklet created by Autistic Self Advocacy Network, the Autistic Women and Nonbinary Network, the Thinking Person's Guide to Autism, and Little Lobbyists.

<https://tinyurl.com/xz8wkm2z>

Research Articles

A Good Night's Sleep: Learning About Sleep from Autistic Adolescents' Personal Accounts by Georgia Pavlopoulou. "Our study provides evidence that healthcare practitioners should go beyond providing a standardized sleep hygiene handout and instead collaborate with autistic adolescents to co-create a personalized sleep set of habits." Open access.

<https://tinyurl.com/26385kaw>

"Autistic parents' views and experiences of talking about autism with their autistic children" by Laura Crane, Lok Man Lui, Jade Davies, Elizabeth Pellicano. *Autism*, 2021, May 25(4), pp1161-1167 (open access)

<https://tinyurl.com/u73nzuzx>

"Everyone Deserves AAC: Preliminary Study of the Experiences of Speaking Autistic Adults Who Use Augmentative and Alternative Communication" by Amy L. Donaldson, Endeavor Corbin and Jamie McCoy. Inclusive research study about autistics who use AAC by a research team that included a speaking autistic adult who uses AAC.

https://pubs.asha.org/doi/10.1044/2021_PERSP-20-00220

"No Way Out Except from External Intervention: First-Hand Accounts of Autistic Inertia" by Karen Leneh Buckle, Kathy Leadbitter, Ellen Poliakoff and Emma Gowen. This study, called for by autistic people and led by an autistic researcher, is the first to explore 'autistic inertia,' a widespread and often debilitating difficulty acting on their intentions. Previous research has considered initiation only in the context of social interaction or experimental conditions. This study is unique in considering difficulty initiating tasks of any type in real life settings and by gathering qualitative data directly from autistic people. Open access.

<https://tinyurl.com/cr8u5rns>

Videos

LEARN FROM US, a 3 minute version of the film LISTEN, from CommunicationFIRST, with the restraint scene removed

<https://youtu.be/ooKVxwVt8il>

Educational toolkit for the film LISTEN, subtitled versions in 6 different languages (Spanish, French, German, Brazilian Portuguese, Greek, and Italian), audio-described versions, and other versions here:

<https://communicationfirst.org/listen/>

#LiberatingWebinars:Abolition,Deinstitutionalization, and Decarceration in the Pandemic — discussion with Dustin P. Gibson and Shain M. Neumeier about connections between disability justice and abolition, January, 2021. Hosted by Autistic Women and Nonbinary Network (AWN), moderated by Lydia X.Z. Brown (52 minutes; captions; sign language interpretation)

<https://youtu.be/wVoLbGMZfcE>

AuTeach: #stoptheshock with Lydia X. Z. Brown and Shane Neumeier — discussion of how we move forward as a community to fight against the torture and inhumane treatment of individuals at the Judge Rotenberg Center and elsewhere (1 hour; captioned)

<https://tinyurl.com/3mtazpe2>

Understanding Sensory-Motor Differences and the Impact of Neurological "Noise" in Autism with Dr. Dana Johnson, PhD, MS, OTR/L, Dr. Elizabeth Torres, Ph.D., and Jen Schonger, New Jersey Autism Center for Excellence (2 hours; captioned)

<https://youtu.be/snJNZrvTdLg>

Toolkit:

LISTEN to Us - A Toolkit About Nonspeaking Autistic People, Meltdowns, and Seclusion and Restraint. "This toolkit is designed to be a beginning resource for people who want to learn more about nonspeaking autistic people, methods of communication other than speech, disability representation in media, autistic meltdowns,

trauma-informed care for autistic people, restraint and seclusion and their alternatives, and how to best support nonspeaking autistic people and survivors of restraint and seclusion. It is not meant to be a singular resource, and we encourage you to view the different resources, especially those

written by nonspeaking autistic people, linked in this toolkit.” By CommunicationFIRST, the Autistic Self Advocacy Network, and the Alliance Against Seclusion and Restraint, February 12, 2021
<https://tinyurl.com/3bmw3upw>

Resources

The Significance of Semantics: Person-First Language – Why It Matters” by Lydia X. Z. Brown, Autistic Hoya blog.

<https://tinyurl.com/ke46nhxh>

“Beyond Guardianship: Toward Alternatives that Promote Greater Self-Determination for People with Disabilities”

<https://tinyurl.com/nw4tycfz>

“Coping with a Crisis When You Have Unreliable or Intermittent Speech” by Maxfield Sparrow, Unstrangemind.com

<https://tinyurl.com/b2vrhbty>

“Forcing Friendships Doesn’t Equal Autistic Youth Gaining Social Skills” by Kerima Çevik

<https://tinyurl.com/bjmhvxx5>

“Mental Health Therapy and the Autistic Client: When Clinicians Don’t See the Autism (Can’t See the Forest for the Trees)” by Judy Endow

<http://www.judyendow.com/category/autism-and-mental-health/>

“Supporting a Person Who Is Experiencing Post Traumatic Stress Disorder (PTSD)” by David Pitonyak.

<https://tinyurl.com/cb46vrha>

Trigger warning: In the following sites, there is discussion of institutions, trauma, the use of pain, and ABA.

“Bearing Witness, Demanding Freedom: Judge Rotenberg Center Living Archive – Living Archive & Repository on the Judge Rotenberg Center’s Abuses” by Lydia X.Z. Brown. This page contains

links to a variety of materials relating to the Judge Rotenberg Center (JRC), formerly known as the Behavior Research Institute (BRI) (living archive last updated 12 July 2021)

<https://autistichoya.net/judge-rotenberg-center>

“ABA Therapy and PTSD” by Amy Grant, M.S., CCC-SLP, Senior Advisory Panelist for the Therapist Neurodiversity Collective

<https://therapistndc.org/aba-therapy-and-ptsd>

Coming in October, 2021 – *Pain and Shock in America: Politics, Advocacy, and the Controversial Treatment of People With Disabilities* by Jan Nisbet, distributed for Brandeis University Press, with Contributions by Nancy R. Weiss — the first book to be written on the Judge Rotenberg Center and their use of aversives as “treatment” for children with disabilities. This book is a historical case study of the Judge Rotenberg Center, named after the judge who ruled in favor of keeping its doors open to use aversive interventions. It chronicles and analyzes the events and people involved for over forty years that contributed to the inability of the state of Massachusetts to stop the use of electric shock and other severe forms of punishment on children and adults with disabilities. It is a long story, sad and tragic, complex, filled with intrigue and questions about society and its ability to protect and support its most vulnerable citizens.

<https://tinyurl.com/ejnmh7jev>

Thumbs Up and Thumbs Down

Thumbs Up

The National Council on Independent Living adopted (on July 21, 2021) Resolution Opposing Applied Behavioral Analysis (ABA). It reads in part, "BE IT RESOLVED that ABA is a harmful and abusive practice that the National Council on Independent Living (NCIL) opposes in all its forms . . ." To read the entire resolution:

<https://tinyurl.com/2k8353nc>

The Department of Health and Human Services (HHS) recently appointed a significantly increased number of autistics, including full-time AAC user Hari Srinivasan, to the Interagency Autism Coordinating Committee (IACC)

<https://tinyurl.com/977mztx4>

The U.S. Justice Department has resolved an ADA complaint with Maine Department of Health and Human Services. Maine DHHS will now provide access to all needed in-home services for the complainant and pay \$100,000 in damages. The department also found that Maine failed to modify its service program for people with intellectual disabilities or autism to avoid discrimination. Maine will now modify its policies so that people with intellectual disabilities or autism can receive services in their homes.

<https://tinyurl.com/4s7j66cj>

The U.S. Supreme Court rejected another challenge to the Affordable Care Act (ACA) in a 7-2 ruling in the case of Texas v. California, in its third ruling in favor of the Obama-era healthcare legislation, which has been vital to people with disabilities.

<https://www.ndrn.org/resource/supreme-courts-aca-ruling-a-relief-to-people-with-disabilities/>

Governor Ralph Northam of Virginia issued a full pardon for Neli Latson, a Black man with multiple disabilities sentenced to prison as a teenager. Mr. Latson's family, advocates, and advocacy organizations had been seeking justice for Mr. Latson for more than a decade.

<https://autisticadvocacy.org/2021/06/advocates-applaud-full-pardon-of-neli-latson-a-young-black-man-with-disabilities-after-decade-of-injustice/>

A small but growing number of states have banned or are in the process of taking steps to ban the practice of paying people with disabilities subminimum wages. This list now includes Alaska, Maine, Maryland, New Hampshire, Oregon, Washington, Hawaii and Colorado. APSE (Association of People Supporting Employment First) is keeping track of the progress.

<https://apse.org/state-legislation/>

Thumbs Down

The Supreme Court overturned the FDA regulations prohibiting the use of electric skin shock for behavioral control, thus allowing the Judge Rotenberg Center in Massachusetts (the only site in the US to use it) to continue this horrible, painful, traumatizing practice. AutCom is appalled and outraged by this outcome.

<https://tinyurl.com/u2888aj9>

The US Navy rescinded a student's ROTC scholarship because of his autism diagnosis. Tory Ridgeway was accepted to Embry-Riddle University on a full NROTC Scholarship in April. In June, that scholarship was rescinded because of his autism diagnosis.

<https://tinyurl.com/u2888aj9>

Fall Down 7 Times, Get Up 8

A Young Man's Voice from the Silence of Autism

by Naoki Higashida – Random House, 2017
Reviewed by Anne Carpenter

Books written by people who are more disabled by autism, having more difficulty with communication, movement and emotional regulation, and sensory processing, are often lost in the shuffle. As a result, individuals with these complex issues (sometimes called “severe autism”) are not as well understood. Naoki Higashida sought to shine a brighter light on these lives with his bestselling book, *The Reason I Jump*, in which he wrote about his experience with autism as a young boy.

Now a young man in his twenties, he has written another gem. *Fall Down 7 Times, Get Up 8* continues where he left off, but he must now contend with the frustrations that adulthood brings, such as continuing to need support and help with everyday functioning, including communicating wants and needs. Using a letter grid that was improvised by his mother, he communicates through a laborious process of selecting the letters one by one, often distracted by other things going on around him. Although to an observer he may appear to not understand what is going on, his writing reveals a treasure-trove of impressions and thoughts, such as why he lets the bath water get cold, even when it is cold outside, and his frustration at an umbrella that wouldn't close shut until his mother showed him the corroded, rusty fastener—then, he was able to accept that

he couldn't close that umbrella.

The book is divided into sections, including The View From Here, Speech Bubbles, School Years, Inner Weather, Handle With Care. Each chapter focuses on a specific aspect of his life and how he does everything he can to work around the many challenges he faces everyday. Naoki continues to grow, change and learn, but he still must contend with distractions, meltdowns, obsessions and continuing difficulties with communication. His alphabet grid allows him to open the door allowing others to view a mind that often processes the world more intensely. That necessitates more effort in doing what we take for granted everyday, such as dressing, bathing, eating meals and getting around town. He does not have a job or a girlfriend and continues to need support, so he lives with his parents in Japan. His family is a loving one, which makes a world of difference!

I just loved this book to pieces. It is beautifully written, yet easy to understand and to help the reader know what hoops the author has to jump through, just to get through another day. One can feel his anger and frustration, but also his compassion and hope in the face of great odds. Another person could crumble under this great weight, but Naoki Higashida has resolved to stand tall.

Real

by Peyton Goddard and Carol Culec
Reviewed by Anne Carpenter

Peyton Goddard, who wrote *Helium Hearts* and *I Am Intelligent*, is a woman who grew up with autism but experienced a great deal of difficulty with communication until she was introduced to typing with assistance. She went on to graduate as Valedictorian from Cuyamaca College in San Diego.

Her latest book, co-written with Carol Culec,

is a novel, *Real*, which is based on her life as a teenager. The protagonist, Charity, was diagnosed as “low-functioning autistic” by the people she has called “The Thinkers,” professionals with little understanding and narrower, outdated ideas about disability, movement and unused potential. Even that dreaded “R” word was used to describe Charity and her difficulties.

As the story proceeds, Charity continues to be misunderstood, such as at her aunt Elvi's wedding, where her aunt judged her as too disabled to participate in society. But the true heart of the story is her time at Borden Academy, a school for children with autism, learning challenges, and cognitive impairments (that she calls Boredom Academy), which turns out to be rife with abuse and mistreatment of its students, including seclusion and leaving students alone on the playground.

Yet she makes friends with Isabella, a fellow student whom she feels is also being mistreated by the school. Hating every minute of this school, it is arranged for her to try out inclusion in a regular middle school, at Lincoln Junior High. But her journey was fraught with challenges, as Charity had difficulty controlling her body which made communication difficult, if not impossible.

One way of coping was to memorize animal

facts from an encyclopedia. This book is studded with fascinating little tidbits about animals, from aardvark to zebras, along with the corresponding page numbers.

Her ticket to freedom is working with an aide to assist her in communicating using a keyboard that also says what she has typed, helping her to make real progress. But as she tries to find a way to liberate Isabella, who is still stuck at Borden, the path becomes rocky and treacherous. She speaks to the heart, quoting the great Frederick Douglass about liberation and giving everyone a voice and a chance.

I was so moved by this book. One can see the potential and passion shine through as Charity makes her way through the choppy waters of adolescence, autism and life itself. She does not take "No" for an answer, and neither should we.

Principles of the Autism National Committee

As a member of the Autism National Committee I endorse for all people with autism, pervasive developmental disorders, and related disabilities the development of high-quality community services, including education, residences, jobs/job training programs, and of individualized support services in all locations for both individuals and their family members; of state-of-the-art communication options for all individuals with unique communicative and social needs; of adequate supports to every family to assist them in maintaining their family member with a disability in their home at least throughout the childhood and adolescent years; and the dissemination of available knowledge of those aspects of the disability requiring special support and understanding; the promotion of research to provide parents and professionals with greater insight into the unique needs of individuals with autism and related disabilities; and the use, development, and promotion of positive, respectful approaches for teaching every aspect of life.

Moreover, I oppose the use of institutions to separate people from their communities, and deprive them of dignity, freedom and the level of independence they can achieve in supportive community living; the use of procedures involving pain, humiliation, deprivation, and dangerous drugs as a means to alter and control individuals' behavior; the increasing use of bizarre technology to control self-injurious and aggressive behavior; the widespread ignorance of the basic social and communicative needs of people with autism; and the widespread disregard for the individual's unique, basic and human needs. I object to programs which disregard the skills, preferences and basic human needs of the people they serve, and I believe that there is no longer need or any justification for using painful and abusive procedures.



Time to Renew or Join Today!

Annual membership begins in January



AutCom Annual Membership Form

Join any time. Renew each January (except for Lifetime Members).

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Newsletter by email or in printed form when available

I want to Renew my membership Become a member

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Enclosed is my membership fee of: \$10.00 (autistic person)

\$30.00 (regular membership) \$10.00 (student membership)

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I am enclosing an additional \$ _____ donation to speed up the good work!

As a donor, I want to be listed by name anonymously.

Send this form or a copy and a check payable to Autism National Committee to

PO Box 115
Oberlin, OH 44074

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Autism National Committee
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Time to Renew or Join Today!

Annual membership begins in January
Membership form on page 20.



The Communicator

The **COMMUNICATOR** is a publication of the Autism National Committee, Inc., a 501 (c) (3) charitable organization founded in 1990 to protect and advance the civil rights of people with Autism/Pervasive Developmental Disorder and related disorders of communication and behavior. Contributions of articles, information and letters are welcomed. The Communicator does not carry advertising or fund raising announcements, and we reserve the right to edit all submissions. Your comments are actively sought. Send them to communicator@autcom.org

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