Volume 24 no. 3, Fall 2025

The Communicator

A publication of the Autism National Committee

Introduction

Thirty-five years ago, the founders of The Autism National Committee established it as a human rights organization. Since then, we have witnessed a number of positive changes in our society's understanding of autism and in support for autistics and their families. The term "neurodiversity," invented by autistic self-advocates, is now part of our general cultural parlance. Increasingly, groups are replacing "autism awareness" activities with "autism acceptance." Many people formerly confined to incredibly oppressive institutions now participate actively in their communities. Even as we note these improvements we see the emergence of new threats to the rights and dignity of autistics. At the highest levels of the US government, autism is now being portrayed as a tragedy, a disease, and an epidemic. We are currently witnessing attempts to divide the autistic community into those with "profound" or "severe" impairments and those described as "higher functioning" - presumably as a rationale for denying basic human rights to some. Both Maxfield Sparrow, in his article, and Dr. Stephen Kapp, in his recent webinar, address this issue. In contrast to those who would portray autism as a "tragedy," AutCom continues to celebrate the strengths and creativity of autistics. In this issue, for example we include poetry and artwork by Yasmin Arshad and Sujit Karup. We also continue to support political efforts to protect the important gains we have made. To that end we have reinstituted our Distinguished Disservice Award - this time going to a Cabinet member who disgracefully perpetuates the "autism as a tragedy" myth while misusing science to promote his personal ideology.

In This Issue

Letter from the President

Greetings to all,

Another year has passed, and AutCom has been humming along. This year we held two webinars. The first one was a joint presentation by AutCom Board members Sujit Kurup and Jamie Burke, who shared information on their own sensory and motor issues, discussed how these have affected them as autistics, and detailed the many strategies they use on an ongoing basis to stay regulated. The second webinar was by esteemed professor Dr. Steven Kapp in the UK, who spoke about the long-lasting negative effects of labeling and standardized testing. As an SLP, I experienced firsthand the dilemma of testing students when they were at the mercy of their bodies, which often refused to move as they wanted. Dr. Kapp reminded us that one bad test result can label and follow the unfortunate test-taker around for years, limiting them in every way possible. He suggested ways to accommodate people with disabilities so they can succeed and be heard, and ways for educators and caregivers to advocate for fairer testing. Dr. Kapp is himself autistic, and has faced his share of challenges. We at AutCom are grateful for both presentations. You can find them on our website.

In the coming year we will delve into Mental Age Theory, with a presentation by our new Vice President, Ivanova Smith. Ivanova is a Disability Rights advocate who is Community Collaboration Program Manager for the Developmental Disability Community Services Division of Home Community Living Administration in Washington state. That webinar is scheduled for February 28, 2026. Another one in the works will focus on Supported Decision Making. Stay tuned for more information.

The events of this year have brought forward a troubling reality: the financial and political structures we thought would continue to support people with disabilities have dwindled and, in some cases, may disappear altogether. Disabled people are once more being marginalized and even forgotten. Some influential groups are actively trying to weaken the Home and Community-Based Services Integrated Settings Rule, which could force some disabled people into very restrictive settings (think institutions) and remove their ability to make decisions that impact their lives. We have increasingly seen that when mass numbers of people speak up, they are heard. ASAN and the ACLU are especially active in this arena. We urge you to be informed and to help.

As President of AutCom for the past 5 years (I know I am well overdue to be replaced), I want to thank our incredibly talented and devoted Board members for their efforts over the years: Judy Bailey, Alan Kurz, Sujit Kurup, Jamie Burke, Ivanova Smith, Yasmin Arshad, Srilata S, Matt Hayes, Dan Bergmann, Maxfield Sparrow, Raesin Caine, and Sandi McClennen. You have made AutCom a welcoming place for all autistics.

I wish everyone a very happy holiday season and hope that 2026 brings some peace to you and yours.

Lisa Keller, President of AutCom

Teaser blurb:

When we divide Autistics into “high” vs “low,” “speaking” vs “non-speaking,” we weaken our own movement. Maxfield Sparrow calls for solidarity across communication styles and support needs.

More Alike Than Different: Rejecting false separations between speaking and non-speaking Autistics

By Maxfield Sparrow

For many years now, I’ve told people that I resonate more with my fellow Autists who type or use other AAC methods to communicate than I do with non-autistic people. Almost without fail, I’m met with skepticism. People see a gap between us—based almost entirely on how we produce words.

As my friend Jamie once put it, I “use my effortless voice.” Someone else might work for every letter of every word. To outsiders, that difference looms large enough to obscure everything we share. When people hear my articulate speech, they assume I need far less support than I actually do. When they see a non-speaking Autist typing equally articulate communication, they assume that person lacks the tremendous skills and strengths I know to be common in my non-speaking friends.

Many non-autistic people can’t imagine that I am more like another Autist—regardless of how they communicate—than I am like my non-autistic peers. But the expectations and assumptions laid on us because of these stereotypes are damaging for all of us.

The Problem with Artificial Divisions

Autistics have long been sorted into categories designed to make us easier to “understand”: high- vs low-functioning, mild vs severe, verbal vs non-verbal. These aren’t neutral descriptors. They create hierarchies. They imply that some of us are closer to an arbitrary idea of “normal” and therefore more worthy of rights, while others are so “different” that even basic dignity becomes negotiable.

What those divisions miss is that our neurology is similar. Our needs may look different on the surface, but the ways we process the world—our sensory landscapes, our communication barriers, our thought patterns—are far more alike than they are different.

Why These Divisions Persist

Artificial divisions are convenient for systems that already fail us. It’s easier for service providers, policymakers, and the general public to draw a sharp line between “capable”

Autistics and “incapable” Autistics. Those deemed “capable” are offered token inclusion and then expected to assimilate. Those labeled “incapable” are often stripped of autonomy, placed under guardianship, or even institutionalized—sometimes for life—and subjected to interventions most of us would never consent to.

We aren’t assessed as individuals with complex profiles of strengths and challenges—we’re judged by how others perceive us, filtered through stereotypes about our communication or independence. The more those separations are reinforced, the less solidarity we have, and the easier it becomes for harmful practices to continue without challenge.

The Myth of Homogeneous Subgroups

Even well-intentioned stereotypes cause harm. I’ve recently heard the claim that “all non-speaking Autistics are psychic.” I understand the impulse to frame non-speaking Autistics in a way that pushes back against deficit narratives—but sweeping statements erase individuality. They set people up to be disbelieved or dismissed if they don’t match the myth.

People often create “superpower” stereotypes to make difference more palatable, or to give themselves a tidy way to explain something they don’t understand. But replacing one stereotype with another doesn’t lead to understanding. It simply trades one kind of box for a different kind. And even a “positive” box can still be a cage.

The “Except For” Loophole

One of the most troubling patterns I see is when advocates—Autistic or non-autistic—reach for an “except for” clause. A common example goes like this: ABA is harmful and shouldn’t be used on Autistics—except for those with the most significant support needs.

This thinking assumes that some Autists are so unreachable that anything is justified. It paints certain people as unteachable, unfeeling, or less than human.

If a therapy is abusive for one Autistic person, it is abusive for all of us. The level or type of a person’s support needs does not erase their humanity. Solidarity cannot stop at the edge of someone else’s rights.

What True Solidarity Looks Like

True solidarity means recognizing that support needs are not a measure of value. Accommodations are tools for creating access—not a way to sort people into “worthy” and “unworthy” (or any other harmful categorization).

When we refuse categories like “really autistic” vs “overdiagnosed,” “high” vs “low,” “independent” vs “dependent,” we make it harder for those labels to be used as weapons against us. Solidarity means showing up for the rights and dignity of all Autists, even when their needs or communication look nothing like our own.

Final Thoughts

I began by saying I feel more in common with non-speaking Autists than with neurotypicals. That connection is not about how we communicate—it’s about the shared experience underneath: a way of being in the world that is frequently misunderstood, a need for respect on our own terms, and a refusal to abandon any member of our community to discrimination or abuse.

When we reject false separations, we build a movement that is harder to divide, harder to silence, and harder to ignore.

Maxfield Sparrow is an Autistic writer and educator whose work centers lived experience, communication, and disability justice. They are the editor of Spectrums: Autistic Transgender People in Their Own Words and blog at www.UnstrangeMind.com

We applaud . . .

The Commonwealth of Virginia for its new law, enacted July 1, 2025, that requires AAC training in schools: “Students who need or use augmentative and alternative communication; documentation of needs on individualized education program; staff training. Requires each school division to document on the individualized education program of a student with a disability who needs or uses augmentative and alternative communication (AAC) such student's AAC and communication access and support needs prior to the provision of instruction or support to such student, including any extended school year period. The bill defines AAC as any method or tool other than oral speech that an individual uses to communicate, including gestures, facial expressions, writing, and speech-generating devices. The bill also requires each school division to provide to each employee or contractor who provides instruction or direct support to a student with a disability who needs or uses an AAC individualized training as an assistive technology to support the student's use of AAC and to ensure that access to curricula and instruction is designed or adapted as necessary to accommodate the student's unique communication access needs. The bill also establishes a timeline for such training based on certain circumstances.”

Communication First provided leadership in getting this bill introduced and passed, along with support from the Arc of Virginia, the Arc of Northern Virginia, and the Fairfax County Special Education PTA (SEPTA). Here is a link to an explanation of the bill and its importance from Communication First, with links: https://communicationfirst.org/wp-content/uploads/2025/03/2025-03-27-C1st-Release-re-New-Virginia-AAC-Training-Law.pdf

American Medical Association for its Final Policy - Fragrance Regulation H-135.902. The policy:

- Our AMA recognizes that some environmental exposures may have the potential to substantially limit major life activities of an individual with fragrance sensitivity and related disorders.
- Our AMA encourages health care facilities, government agencies, and nonprofit organizations to adopt and promote fragrance-free policies that recommend individuals avoid or limit use of fragrances and support the use of fragrance-free products when feasible in consultation with relevant medical specialists when possible.
- Our AMA encourages research on fragrance sensitivity to;
    - improve diagnostic tools;
    - understand the impact of fragrances on other diseases;
    - evaluate the impact of fragrances on health; and
    - evaluate the impact of fragrance-free interventions.
    - Our AMA supports the identification of fragrance allergens and disclosure of fragrance ingredients as part of labeling of personal care products, cosmetics, and drugs.

https://policysearch.ama-assn.org/policyfinder/detail/fragrance

New & Exciting

"Inspiration in the Midst of Horror," by AutCom Board Member Dan Bergmann and his father Michael was recently streamed via the Global Nonviolent Film Festival.
“In the documentary, Dan visits an empowering exhibit that showcases the courageous Danish rescue of Jews during WWII at the Museum of Jewish Heritage in New York City. Dan is fascinated by the exhibit, which parallels his life experiences and goals, as someone who has faced challenges and needed others' help.”
Watch the trailer here: https://globalcinema.online/programs/global-nonviolent-film-festival-2025?cid=4401076&permalink=inspiration-in-the-midst-of-horror

Now available free online: Spellers: The Movie (Documentary) Spellers Freedom Foundation (1:22:17). Entire documentary. Captioned.
https://youtu.be/8h1rcLyznK0?si=lgH6fzsV1UxLCWnl

The Assembly, a Canadian tv show involving autistics in interviewing celebrities:
“In each episode of this unique entertainment series, one of Canada’s most popular celebrities and public figures faces a group of 30 atypical interviewers, all on the autism spectrum. Featured celebrity guests include Jann Arden, Allan Hawco, Howie Mandel, and Maitreyi Ramakrishnan, with more to be announced. Interviewers include Margaux Wosk and Damon Kirsebom.

- This video features clips from an interview with Margaux Wosk, autistic entrepreneur and disability rights advocate. https://youtu.be/EXGJ3aWstKw

- This video features Damon Kirsebom, who types to communicate, posing a question: "I was denied access to a full education" - Damon Kirsebom asks 'Never Have I Ever' star Maitreyi Ramakrishnan about her advocacy efforts. Damon, someone who was denied access to a full education because he is non-speaking, wants to know why Maitreyi uses her platform to talk about inclusion. https://youtu.be/lp7qCdnugQk

Resources

Films and Video:

Elizabeth Bonker: Empowering Nonspeakers with Communication and Education. Think Inclusive blog by Tim Villegas. July 31, 2025. Podcast. (36:04) “Tim Villegas engages in an enlightening conversation with Elizabeth Bonker, a prominent advocate for non-speaking individuals. Elizabeth shares her inspiring journey of becoming a voice for non-speakers through typing. Despite the communication barriers she faced,

Elizabeth emerged as a powerful force in advocating for inclusivity in education and society."
https://www.youtube.com/watch?v=xp8cqmsbOqY

Grant Blasko: Systemic social isolation of AAC users. Video of Grant Blasko's presentation at the Future of AAC Research Summit in 2024. (The paper by Blasko is to be published in the AAC Journal.)
https://aac-learning-center.psu.edu/2025/05/16/blasko-2024/

Spellers: The Movie (Documentary). Spellers Freedom Foundation (1:22:17). Entire documentary. Free online. Captioned.
https://youtu.be/8h1rcLyznK0?si=lgH6fzsV1UxLCWnl

Blogs:
The Listening World. "The Listening World is a weekly newsletter featuring poems and songs created by neurodivergent writers in partnership with Unrestricted Interest."
https://thelisteningworld.substack.com/about

Unrestricted Interest is a home for neurodivergent listening, learning, and languaging. Its publishing imprint, Unrestricted Editions, features many chapbooks (both hardcopy and digital) from neurodivergent writers throughout North America.
https://www.unrestrictedinterest.com/

Unstrange Mind: A Bridge Between Silos. Maxfield Sparrow. "Autism isn't two categories—it's an ecosystem. In my new essay, A Bridge Between Silos, I explore what it means to live in autism's "messy middle": early-identified but late-understood, too verbal for compassion yet too volatile for comfort. When we divide autism into "profound" and "non-profound," we erase all the people whose lives are too complex to stuff into a silo."
https://unstrangemind.com/a-bridge-between-silos

Articles

Grant Blasko (2025). Unveiling underlying systemic isolation challenges for AAC users. Augmentative and Alternative Communication, 1–8.
https://doi.org/10.1080/07434618.2025.2515279
This paper is one in a series from the Future of AAC Research Summit to be published in the AAC Journal. A video of Blasko's presentation of the paper can be viewed at
https://aac-learning-center.psu.edu/2025/05/16/blasko-2024/
Student Notebook: The Physics of Autistic Inertia. Hari Srinivasan. August 28, 2025. "Autistic inertia describes the difficulty autistic people face in starting, stopping, or switching tasks; a concept first articulated in autistic community narratives."

https://www.psychologicalscience.org/publications/observer/student-notebook-autistic-inertia-srinivasan.html

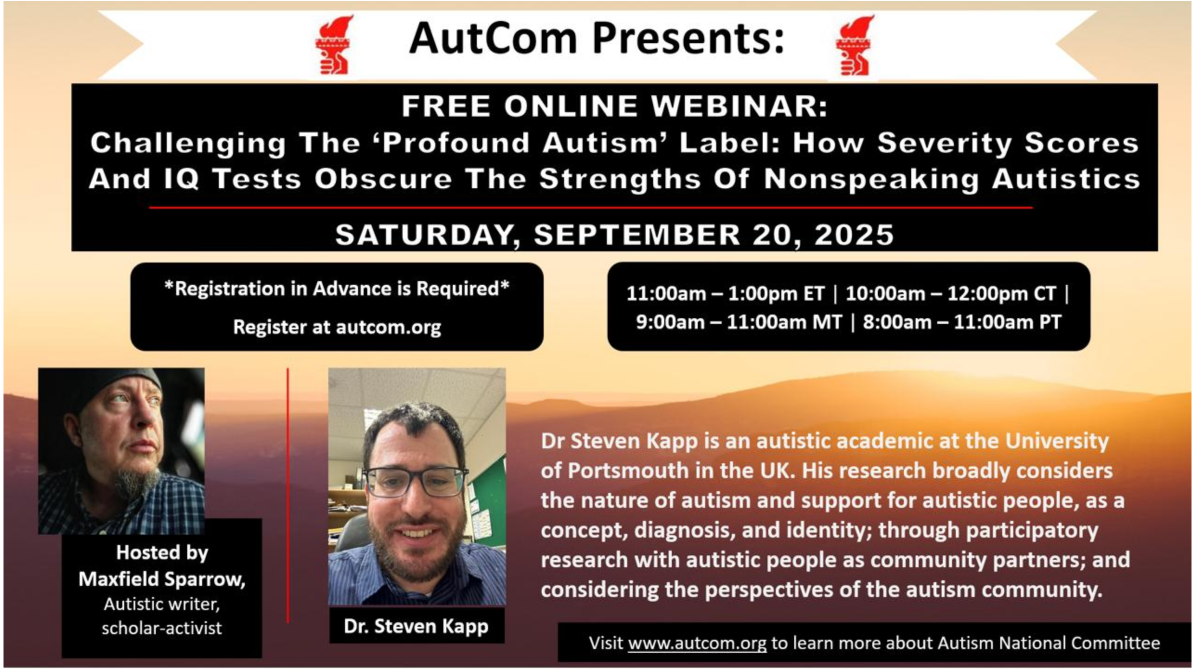
“For families like mine in Maryland and across the country, these decisions aren’t abstract. We don’t need empty promises of imminent discoveries — we need sustained commitments to evidence-based research and the supports that make daily life possible.” When autism promises and policy collide. Baltimore Sun, Guest Commentary by Linda Orleans, Oct. 22, 2025.
https://bit.ly/4odIU0v

Why ABA Can Never Be Trauma-Informed: Not now. Not ever. Alliance Against Seclusion and Restraint, October 20, 2025.
https://endseclusion.org/2025/10/20/why-aba-can-never-be-trauma-informed-not-now-not-ever/

Child neurologists can play a critical role in identifying movement issues in autism, but more training is needed. Only 36% of neurologists identified that motor impairments are an associated feature of autism. “A new UCLA Health study highlights concerning gaps in how child neurologists understand and address motor difficulties in children with autism, despite research showing these movement problems affect the majority of autistic children and can significantly impact their development. The study, published in the journal Pediatric Neurology, found many child neurologists are not aware that motor impairments are an associated deficit of autism and often lack important education around this in training.”
https://www.uclahealth.org/news/release/child-neurologists-can-play-critical-role-identifying

Media:
PBS Kids Show to Feature Character Who Uses Communication Device, by Shaun Heasley. October 8, 2025
https://www.disabilityscoop.com/2025/10/08/pbs-kids-show-to-feature-character-who-uses-communication-device/31668/

Challenging the ‘Profound Autism’ Label: How Severity Scores and IQ Tests Obscure the Strengths of Nonspeaking Autistics -- Webinar Recording Now Available for Viewing



AutCom Presents:

FREE ONLINE WEBINAR:
Challenging The ‘Profound Autism’ Label: How Severity Scores And IQ Tests Obscure The Strengths Of Nonspeaking Autistics

SATURDAY, SEPTEMBER 20, 2025

Registration in Advance is Required
Register at autcom.org

11:00am – 1:00pm ET | 10:00am – 12:00pm CT | 9:00am – 11:00am MT | 8:00am – 11:00am PT

Dr Steven Kapp is an autistic academic at the University of Portsmouth in the UK. His research broadly considers the nature of autism and support for autistic people, as a concept, diagnosis, and identity; through participatory research with autistic people as community partners; and considering the perspectives of the autism community.

Hosted by
Maxfield Sparrow,
Autistic writer,
scholar-activist

Dr. Steven Kapp

Visit www.autcom.org to learn more about Autism National Committee

AutCom (Autism National Committee) is pleased to announce that the video recording for our most recent webinar, Challenging the ‘Profound Autism’ Label: How Severity Scores and IQ Tests Obscure the Strengths of Nonspeaking Autistics by Dr. Steven Kapp, is now available for viewing free online. This free online webinar aired on September 20, 2025. AutCom Board Member Maxfield Sparrow introduced Dr. Kapp, and moderated the Q&A which followed.

Steven Kapp, Ph.D., is an autistic academic at the University of Portsmouth in the UK. His research broadly considers the nature of autism and support for autistic people, as a concept, diagnosis, and identity; through participatory research with autistic people as community partners; and considering the perspectives of the autism community. He has critiqued profound autism, functioning labels, and severity scales and published on autism as a lifelong neurodivergence based in sensory and movement differences, as well as on the strengths of autistic people with speech divergence.

The webinar video recording is available at the following link with corrected captioning and a transcript. There is also a list of links to specific sections of the webinar to make it easy to navigate to them. Thanks to Maxfield Sparrow for the editing, captioning, and convenient navigation links. https://www.youtube.com/watch?v=dfE7u8QpMnA

Rebirth.

More than wise,
Older than death,
Never stopping,
So marches time.
But when I gaze up at the stars,
My overwhelmed mind sees
Hopeful shapes of the distant
Birth of the universe,
Constantly reborn.
And my heart heals
Knowing all is infinite,
And I too am dust of stars!
My star is in my heart,
Hope is in that star.
And we shall be together
Forming stars.
For all eternity

-Yasmin Arshad

My name is Yasmin Arshad. I was born in Florence, Italy, and came to the US at age 7. I'm bilingual. My awesome mother found me the ideal workplace when I turned twenty-two: a studio for artists with disabilities, Gateway Arts in Brookline, MA. I am a successful artist; my art sells at the Gateway store. I have exhibited at the Fuller Art Museum, Brockton, MA., the Outsider Art Fair in NYC, in London and in Tokyo. I write poetry, enjoy traveling, walking, horseback riding, snow shoeing, and going to the symphony. I live with my parents part of the week, and with my caretaker and good friend the rest of the week. I was an ideal subject for the Lurie Center's research program on Facilitated Communication. When I first started typing to communicate no one could believe how much I knew; no one believed I could read. But I have been reading since I was 4. I enjoy pondering the Big Questions: what is the origin of life? of eternity? My true joy in life is now being able to communicate. I'm very happy to now be able to type to communicate; it makes such a difference in my otherwise lonely life of an autist.

My best, Yasmin

My Crowded Mouth

With my head full of thoughts,
As tears fill my heart,
I dream I am telling you
All of my fears.
Waking up, I discover
All my words still are stuck.
My teeth -a portcullis
Barring all words from escape.
Nothing gets out.
Imprisoned words crowd,
Stuck to the palate roof
Of my impregnable mouth.
And my throat is too tight!
Like fish gasping for air,
I flounder and writhe.
Certain death to my prayers.
My wishes wither;
My thoughts abandon hope.
Knowledge has taught me
Words I can’t shout.
All quiet on this front:
In this lifelong battle
No words can escape
My poor crowded mouth.

- By Yasmin Arshad

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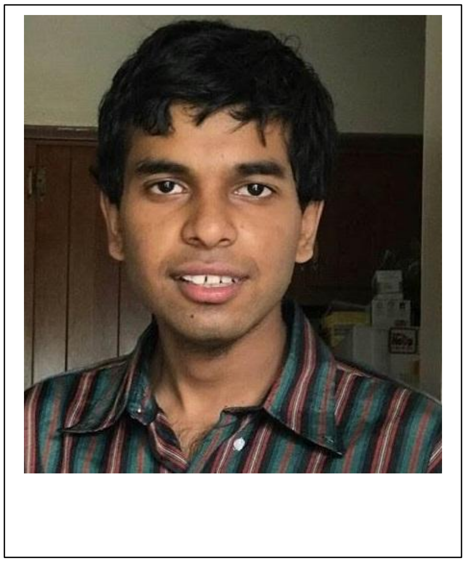

Contremplative Gaze
Of Humanity

Sujit Kurup
(About me)

I am very passionate about my painting. I have been painting for about 15 years with many mediums, mostly with abstract painting on acrylic.
I am an autist, minimally speaking and painting provides a level playing field to express innermost thoughts and emotions with the brush. It is a great medium to communicate my real nature, showcasing my intelligence and creative mind.
Picasso's abstract art and lately Kandinsky's Impressionist art are my inspirations.
Jackie Adamo from Adamo Studios has mentored me for a long time. Now I work with Iver Johnson, Portrait drawing specialist.

My art has been regularly exhibited at the:

- Rochester Contemporary art gallery, Rochester, NY (6"x6") and Member exhibitions,
- Everson Museum, Syracuse, NY through Unique magazine of the ARISE Inc,
- Art for Art's Sake through CNY (Central New York) Arts where I got the Second place for the theme "Solitude"
- Nappi Wellness center, Upstate University as a permanent display (2023)
- Cancer Center, Upstate University Hospital: In 2020 (5 paintings) and will be on display 2026-27(10 paintings)
- Have been featured on cover of M&T Bank Annual report (collage) (2021)

You can contact me at sujitkurup09@gmail.com/315-9305466 for more information on my artwork.

Return of the *Distinguished Disservice Award*

*Vaccines do **not** cause autism. Vaccines let autistic children live long enough to become autistic adults. Autism is not a tragedy to be prevented; it is a way of being deserving of support and respect.*

Autistic Self Advocacy Network

After many years AutCom has decided to reinstitute our *Distinguished Disservice Award* - in part because few people have ever been more deserving than this year's recipient - **Robert F. Kennedy Jr.** Reasons for him receiving the award include:

- RFK Jr.'s *portrayal of autism as an epidemic and a "disease" to be eradicated*. Rather than seeing autism as a part of natural human diversity, he has repeatedly described it as a disease occurring at epidemic levels. Of course, he ignored evidence of that apparent increase in diagnosis could be due to changing diagnostic criteria, greater surveillance or to the fact that other diagnoses were collapsed into ASD in the DSM 5.

- *He falsely and derogatorily described the life outcomes of autistic individuals*, saying: "And these are kids who will never pay taxes, they'll never hold a job, they'll never play baseball, they'll never write a poem, they'll never go out on a date. Many of them will never use a toilet unassisted."

- *He prioritizes research on causes and cures.* Consistent with his view of ASD as a disease, RFK Jr. has prioritized research on the causes of and cures for autism rather than on effective supports. Absurdly, in April of this year, he claimed they would find "the cause of autism" by September. In doing so, he assumed a single environmental cause of autism would be identified while ignoring the thousands of studies that have already been conducted (mostly identifying genetic factors). The focus on causes also runs counter to the research priorities of both autistic individuals and family members.

- *RFK Jr. continues to claim causal connections between the development of autism and various environmental factors without legitimate evidence.*

  - RFK Jr. falsely claimed that Tylenol taken by pregnant mothers causes autism based on one poorly designed study while ignoring a number of other well-designed studies showing no relationship. A review of comprehensive reviews and meta-analyses in the British Journal of Medicine found no clear link between Tylenol and an autism diagnosis.

  - He has continued to claim that vaccines cause autism by cherry-picking data. In one case, he cited a study that included just nine autistic individuals. RFK Jr. personally changed the CDC statement on autism and vaccines with a statement that read: "The claim 'vaccines do not cause autism' is not an evidence-based claim because studies have not ruled out the possibility that infant vaccines cause autism." This reveals a shocking misunderstanding of how science is done and is equivalent to saying: "The claim that there is not a pot of gold at the end of the rainbow" is not evidence-based because studies have not ruled out the possibility that leprechauns have indeed buried a pot of gold at the end of the rainbow. The Infectious Diseases Society of America condemned the change in wording at the CDC stating: "There is no scientific rationale for the CDC to change its long-standing assertion that there is no link between vaccines and autism. The change is not driven by science but by politics and will only serve to increase mistrust in science and medicine."

- *Threatening the health of Americans by rejection of solid science and instead being guided by ideology*.

  - Six former surgeons general, serving both Democratic and Republican Presidents, stated: "Today, in keeping with those oaths, we are compelled to speak with one voice to say that the actions of Health and Human Services Secretary Robert F. Kennedy Jr. are endangering the health of the nation..."

  - RFK Jr. has repeatedly lied about the safety and efficacy studies done on vaccines. He replaced the entire Advisory Council on Immunization Practices (ACIP) because they were not all on board with his vaccine misinformation. Most recently this council eliminated the recommendation that all infants receive the Hepatitis B vaccine. As the Autistic Self Advocacy Network has pointed out recently: "The presenters at the ACIP meeting claiming that vaccines need to be “depoliticized” are the very same charlatans placed on this committee to serve as puppets for HHS Secretary Robert F. Kennedy Jr.‘s anti-science, conspiratorial, anti-health agenda that endangers all of us."

  - He has repeatedly misrepresented research findings. For example, on a Joe Rogan podcast, he described a 2003 study in which researchers supposedly fed children tuna fish sandwiches. They didn't! He also lied about the study outcomes.

  - RFK Jr. cites imaginary studies to support his positions. RFK's Health and Human Services released its first Make America Healthy Again report with AI-created citations for studies that did not exist but did support RFK's otherwise unsupported claims. The administration claimed this was a "formatting error." It was not.

  - In addition to portraying autistics in very derogatory ways, RFK Jr. is negatively affecting overall health of all Americans by diminishing the capacity to conduct important medical research. 5000 Health workers at the US Centers for Disease Control and Prevention and other government health agencies have told him to stop spreading misinformation and endangering public health. in an open letter to Congress the said that statements made by Kennedy were “dangerous and deceitful.”

This rationale for awarding RFK Jr. the Distinguished Disservice Award is necessarily incomplete. He provides new reasons for deserving the award on an almost daily basis. Congratulations Secretary Kennedy!

FDA Ban on the Use of Electric Shock Devices Is Delayed Again

We received an update from our friend and colleague Nancy R. Weiss, MSW, of the National Leadership Consortium on Developmental Disabilities, regarding the FDA Ban on Electric Shock Devices this fall. Unconscionably, the ban has been postponed 7 months.

Here is what she wrote to us on September 4 this year, encouraging us to spread the word:

Today the FDA published its Unified Agenda for Spring 2025 (see below).

At the end of December '24 the FDA published its Unified Agenda for Fall '25. At that time, they indicated that they planned to publish the final rule on the ban of Electrical Stimulation Devices in October 2025. On the quasi-good news front, today's announcement indicates that the FDA, under the current Administration, still seems to be planning to move forward with this rulemaking; however, now, not until nine more months from now, in May 2026. It is important to note that Unified Agendas, similar to “to do” lists, represent what is planned but do not provide guarantees of any sort. Unified Agendas are often aspirational regarding dates and timelines.

Notwithstanding, it is unclear to me why:

- After being requested to investigate the use of these devices in 2010;
- After convening a panel of expert members of the Neurological Devices Panel of the Medical Devices Advisory Committee in 2014 to seek clinical and scientific opinion on the risks and benefits of using electric shock for behavior control;
- After that panel strongly recommended that these devices be banned;
- After reviewing over 1,500 comments submitted in response to the first two sixty-day comment periods;
- After receiving a petition signed by over 290,000 people calling for these protections in 2018;
- After making the decision and announcing the Ban of Electrical Stimulation Devices on March 4, 2020;
- After over eleven years of careful, additional study since the Neurological Devices Panel met on April 24, 2014 and recommended the ban;
- After opening a third comment period and receiving/reviewing another 8,717 comments submitted in response to this final comment period which closed May 28, 2025 …
  the FDA now feels they need another nine months to finalize and enact a decision that was already made in March 2020.

HHS/FDA RIN: 0910-AI84 Publication ID: Spring 2025
Title: Banned Devices; Electrical Stimulation Devices Intended for Self-Injurious Behavior or Aggressive Behavior
Abstract:
This final rule would ban electrical stimulation devices (ESDs) intended for self-injurious behavior (SIB) or aggressive behavior (AB). FDA intends to review the comments received and assess any new data or information in connection with making a determination as to

whether the use of ESDs for SIB and AB presents an unreasonable and substantial risk of illness or injury and that the risks associated with ESDs for these intended uses cannot be corrected or eliminated by labeling. If FDA makes this determination again, the Agency will issue a final rule to ban these devices. This rule is authorized by section 516 of the Federal Food, Drug, and Cosmetic Act (21 U.S.C. 360f).

Agency: Department of Health and Human Services (HHS)
NPRM 03/26/2024 89 FR 20882
NPRM Comment Period End 05/28/2024
Final Rule 05/00/2026
. . . . . .

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View the Rule here:
https://www.reginfo.gov/public/do/eAgendaViewRule?pubId=202404&RIN=0910-AI84

URGENT CALL TO ACTION

We received a Call to Action from the Maine Parent Federation (MPF), which we find valuable and we are passing along much of what they included below, with a few edits, in this Call to Action, with credit to MPF for their leadership and example.

Call to Action

Reduction in Force at Offices of Special Education Programs & Rehabilitative Services

We have learned that nearly all staff at the federal Offices of Special Education Programs (OSEP) and Rehabilitative Services (OSER) have received a reduction in force notice. This means, unless the notices are rescinded, effective 12/09/2025 these offices will be severely understaffed threatening special education programs in schools and employment offices.

Why This Matters
These offices provide the essential oversight and expertise needed to ensure states properly implement the Individuals with Disabilities Education Act (IDEA) and Section 504 of the Rehabilitation Act.

The impact to State Departments of Education, local schools, and agencies who implement IDEA and Section 504 programming may include a lack of Special Education monitoring, absence of grant approvals, delayed corrective actions plans, limited oversight of special education and civil rights law, and slower response times for assistance, approvals, and appeals.

Most concerning is the threat to the protections and supports that students with disabilities and their families depend on.

What Can You Do
As we have proven already many times during this administration voices of families, providers, and state leaders are extremely powerful.

You can do a couple of things.

1. Send a quick email speaking to your Congressional Delegation about how access to Special Education and Rehabilitative Services are important to you. See below for a template example to use.
2. Call and leave a message for your Congressional Delegation.
3. Finally use the contact forms on your Representative's or Senator's website to send them a message.

NOTE: To find your representative or senator,
Go to https://www.congress.gov/members.
Enter your ZIP code in the search box.
The site will show you the names of your two Senators and your one Representative.

Email Template

Dear __(staffer name)__,

My name is ___(enter name)__and I am contacting you today to express my feelings in regard to the reduction in force action at the Offices of Special Education and Rehabilitative Services. I am concerned these actions will threaten the implementation and oversight of the Individuals with Disabilities Education Act and Section 504 of the Rehabilitative Act.

My experience as a __(here are some examples—autistic, family member, provider, educator)_ with IDEA and/or Section 504 includes __(provide a couple sentences about your experience and why or why not you believe funding should be provided)__.

Thank you for your time and consideration.

_(Your name and contact information)__

Autism National Committee

www.autcom.org
The first autism advocacy organization dedicated
to "Social Justice for All Autistics"
through a shared vision and
a commitment to positive approaches

Principles of the Autism National Committee

As a member of the Autism National Committee, I endorse for all autistics and those with 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 communication 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 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).

For the Annual Membership Year ______________

Name:____ **Date**:_______________

Address:____

City _____________________________ **State** ________ **Zip code** ___________

Phone ___________________ **Email** ___________________________________

I want to ____ Become a Member ____ Renew my Membership

____ Become a Lifetime Member

I am a/an _____ Autistic _____ Family member _____ Friend

_____ Student _____ Professional (field) __________________________

Enclosed is my membership fee of: _____ $10.00 (autistic person - annual fee)

____ $30.00 (nonautistic person annual fee) _____ $10.00 (student annual fee)

____ $75.00 (supporting membership) _____ $500.00 (lifetime membership)

Donation: I am enclosing an additional $________ donation to speed up the good work!

As a donor, I may be listed by name_____ I wish to be anonymous_____

Send this form or a copy and a check payable to <u>Autism National Committee</u> to

AutCom Treasurer
P.O. Box No. 82, 300 Cypress St.
Liverpool, NY 13088-0082

Please note: You may also join, renew your membership, become a lifetime Member, and make a donation at our website: www.autcom.org.

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 fundraising announcements, and we reserve the right to edit all submissions. Your comments are actively sought. Send them to communicator@autcom.org

The COMMUNICATOR Committee
Judy Bailey
Alan Kurtz

AutCom Officers