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The Communicator

A publication of the Autism National Committee

Introduction

In this issue Lisa Keller points out in her *Letter from the President* that AutCom continues "to provide education and advocacy for social justice for all autistics." In many ways the need for advocacy is greater now than any time in the recent past. Both recently enacted and proposed policies threaten the hard-won rights essential for ensuring social justice for autistics, their families and friends. Threats include:

- Medicaid cuts that would reduce community-based supports and medical coverage for many autistics;
- Cuts to Social Security - an important source of income for many autistics;
- Cutting funding to the Administration on Community Living
- Threats to the Individuals with Disabilities Act

Our Congressional representatives and Senators need to hear from us about the importance of programs important to the quality of life of autistics and their families. In his article *Your Voice Matters: A Step-by-Step Guide to Contacting Congress About Autism and Disability Issues,* Max Sparrow provides important information on exactly how to effectively contact and communicate with policy-makers. This article is extremely timely, given the peril disabled people face in the current political climate.

In this issue Dan Bergman also includes a letter to fellow autistics who spell or type to communicate. He calls for a specific action related to advocacy.

This issue contains our regular columns: *We Applaud*, *New and Exciti*ng, and *Resources*. We also provide information and a link to one our recent webinars: *Understanding the Sensory and Movement Dilemma: The Autism Paradox*. As always, we encourage you to share your stories, poems, and essays.

In This Issue

A Letter from the President

Hello to all,

As we kick off Summer ’25, I want to assure everyone that we at AutCom plan to continue our ongoing endeavors to promote the voices of our wonderful members, however they express themselves, and to provide information important to all. We also plan to continue to provide education and advocacy for social justice for all autistics.

In my tenure as president, our Board has held webinars examining how Autistics can be gainfully employed in the community. Autistics have shared how they feel about friendships and deeper relationships (news flash: they want them). Their siblings and parents discussed how having an Autistic family member impacted their family and their perspectives on autism and possibilities. Two of our nonspeaking Board members who type and/or speak to communicate discussed how they achieve sensory and motor regulation through a variety of daily exercises and activities, thus enabling them to gain better control of their bodies to pursue their goals and dreams. (A link to this most recent webinar recording is included in this issue.)

I thought that the webinars were beautifully presented and well-received, and the response from the audiences confirmed that. We had some difficulty with the technical aspect of sharing all the recordings online, but we hope that is behind us now. We plan to make more of our past webinar recordings available in the future.

In the coming months we are looking forward to doing a deep dive into the state of standardized testing, and examining laws that directly affect the most vulnerable members of our community. Watch our website and Facebook page for news of the upcoming webinars. Members will receive email announcements. (Are you a member?)

These are troubled and uncertain times in our country, and we are all feeling the stress that comes with that. AutCom strives to be a quiet oasis in the center of difficult times by offering insight into ourselves and each other and hope in moving forward together.

I hope that you will join me in continuing our efforts. We would like to hear from you. I invite members to send in your letters, commenting on all issues relevant to Autism, sharing your views, poems, essays, etc. We hope to feature artwork and even musical talents on our website or in our newsletter. Send letters and comments to info@autcom.org and send items for consideration for The Communicator to communicator@autcom.org.

There’s so much more to our community than is widely known. Let’s celebrate our members!

With love and friendship,

Lisa Keller

New and Exciting

Speech is Exhausting by endever* corbin. “Having spent years in speech-centric services as a child, I pushed myself to use mouthwords for decades. But the cost was high. Such "expensive speech" is defined as that which may be effective, but has a significant cost in terms of energy, cognitive resources, or other internal resources, affecting what is available for other or later skills or tasks. Multimodal AAC has decreased my cognitive load, freeing up resources for more meaningful participation in society.”
https://www.tandfonline.com/doi/full/10.1080/07434618.2025.2513907?fbclid=IwQ0xDSwK5L6hleHRuA2FlbQIxMQABHskJ6ob7VSraJP9DVOOVX4Pwp8IXKoI97r3LSY3LcD4xhUvPd3Bm9EX01IXU_aem_jj6QD1u4B0iPdbQF_BWJ8w

Next step for nonverbal autistic teen: MIT (Boston Globe, June 23, 2025) tells the story of 19-year-old **Viraj Dhanda**, a nonspeaking autistic teen, once misdiagnosed as intellectually disabled, who has now been accepted to the MIT Class of 2029. The article describes his use of various methods of communication in his journey to express himself fully using technology. “If you choose to go down the path I took, you will experience heartbreak, prejudice and doubt. But it will pale in comparison with the joy of being able to have a voice.” — Viraj Dhanda
https://mobileapp.bostonglobe.com/06232025_514e6c3e-4d53-11f0-bfc4-06e719ff056b/content.html

“Masked Out” a short film by Masina Taule’alo, autistic Writer and Director has been declared an Award Winner by Makizhmithran International Film Festival in Chennai, India. “A university student Tasi, feels the need to mask their autism spectrum symptoms to get through her life. One day, Tasi comes to university to find it completely empty and upon finding there is nobody around, she explores and embraces her autism traits in many fun ways.”
http://makizfilmfestival.co.in/
Masked Out (Short 2024) – IMDb
https://www.imdb.com/title/tt34480473/

Major autism study uncovers biologically distinct subtypes, paving the way for precision diagnosis and care. By Molly Sharlach, Princeton University, Office of Engineering Communications on July 9, 2025. “Researchers at Princeton University and the Simons Foundation have identified four clinically and biologically distinct subtypes of autism, marking a transformative step in understanding the condition’s genetic underpinnings and potential for personalized care.”
https://www.princeton.edu/news/2025/07/09/major-autism-study-uncovers-biologically-distinct-subtypes-paving-way-precision

From Subjects to Scientists: Vanderbilt’s autism research and autistic researchers are reshaping discovery. Vanderbilt Magazine.
https://news.vanderbilt.edu/2025/05/12/from-subjects-to-scientists-vanderbilts-autism-research-and-autistic-researchers-are-reshaping-discovery/

Resources

Claiming Our Space: Voices of Autistic Nonspeakers. Skipping Stones, A Multicultural Literary Magazine. May-August 2025 Issue. Vol. 37, No. 2E.
"One letter at a time is tedious and exhausting, which is why so many spellers end up gravitating towards poetry. As you read the works in this issue, you'll be awed by their intellectual depth, creativity, humor and authenticity! We offer this collection with the hope that you'll see the world through spellers' eyes!"
https://www.skippingstones.org/wp/may-2025-issue/

Sensory–movement underpinnings of lifelong neurodivergence: getting a grip on autism. Steven K. Kapp. "The article closes with implications for autism as a construct (including underestimated empathy and pain), testing the theory, providing sensory-sensitive support and acceptance of autistic people, and applications to diverse autistic people. The theory may apply particularly well to autistic women and girls, autistic people with speech divergence, autistic people with ADHD, and autistic people with co-occurring sensory and motor-related neurodivergences. Throughout the article, the theory also provides clinical, neurological, and experiential evidence for sensory and motor differences as lifelong, challenging the notion of "losing" (an) autism (diagnosis) as instead reflecting (risky and not necessarily "successful") camouflaging."
https://www.frontiersin.org/journals/integrative-neuroscience/articles/10.3389/fnint.2025.1489322/full

Speechless Dream: Narratives on Autism, Inclusion and Hope by Chandra Lebenhagen, Anantha Krishnamurthy, and Janani Ramanath "shares Anantha's poignant interpretation of the harmful effects of therapeutic and educational practices that aimed to remediate his autistic self into something more "normal." Interwoven into his narrative are the stories of the people whose lives intersected because of Anantha's dream to receive an education."
https://books.friesenpress.com/store/title/119734000259484357

"Ought: The Journal of Autistic Culture is a peer-reviewed, biannual journal that publishes scholarly and creative works examining and exploring autistic culture. *Ought* is dedicated to amplifying autistic voices and centering autistic creativity, while including contributions from allistic caregivers, educators, and allies. We strive to create a community that mentors early career researchers, poets, and artists, as well as showcasing the work of leading scholars in the field. *Ought* is committed to celebrating autistic joy and artistry while offering honest and authentic explorations of difficulty and challenge. In blending creative and critical works about autism, *Ought* also seeks to break down barriers between academic disciplines, between genres of artistic expression, and finally, between autistics and allistics. *Ought* is the conversation about autism as it ought to be.*"*
https://scholarworks.gvsu.edu/ought/

Now available: the final report from the Augmentative and Alternative Communication (AAC) Peer Support Project. In partnership with Communication First, OHSU UCEDD Community Partners Council (CPC) has released the final report outlining findings and recommendations for a national peer support plan for people who need or use Augmentative and Alternative Communication (AAC). Check out the full report, executive summary, and plain language version here:
https://www.ohsu.edu/university-center-excellence-development-disability/augmentative-and-alternative-communication-aac

Institute on Community Integration, University of Minnesota website has many interesting articles and podcasts about people with intellectual disabilities, the links are below.
Link for articles: https://ici.umn.edu/series/14
Link for podcast series: https://ici.umn.edu/news/boldly-takes-flight

Loneliness, a Familiar Epidemic, Sarah Hall and Zach Rossetti - Feature Issue on Loneliness and People with Intellectual, Developmental, and Other Disabilities. Institute on Community Inclusion (ICI), Impact. (free, online)
“Being socially connected to others and to experience belonging is important. More people than ever feel lonely, which can have negative physical and health outcomes. The direct support workforce crisis has reduced social opportunities in the community. The loss of funding and programs for people with IDD currently being discussed would make it even more difficult for people with IDD to interact with others in their communities. Social inclusion and belonging should be a priority for all adults with IDD . . . Unfortunately, the loneliness epidemic is not new for adults with IDD and their families. Hopefully, the increased focus on loneliness and social isolation will result in stronger social interactions and relationships for all.” The issue includes twenty-three articles plus sections of poems and resources.
https://publications.ici.umn.edu/impact/38-1/loneliness-a-familiar-epidemic

We applaud:

Well done, Maine! Congratulations to all the advocates and legislators who worked together to accomplish this. We urge all states to follow their example!
Mills signs bill eliminating planned use of restraints for adults with developmental disabilities. Maine Public. By Esta Pratt-Kielley, Published June 13, 2025.
https://www.mainepublic.org/politics/2025-06-13/mills-signs-bill-eliminating-planned-use-of-restraints-for-adults-with-developmental-disabilities

Thank you, New York: A Communication Bill of Rights was passed in New York!
State of New York - 7363--B
“AN ACT to amend the mental hygiene law, in relation to protecting the communication rights of individuals with disabilities
The People of the State of New York, represented in Senate and Assembly, do enact as follows:

New York state communication bill of rights for individuals with disabilities. In order to ensure that each person with a disability is able to lead a life of dignity, all persons with a disability shall have the right to communicate in their preferred manner and all staff and providers under this section, shall have the obligation to ensure and support such rights, which shall include, but not be limited to:
(a) the right to utilize any communication method that meets their needs, including but not limited to:
    (1) augmentative and alternative communication (AAC) techniques and devices;
    (2) spelling boards, letterboards and typing-based communication;
    (3) sign language and non-verbal gestural systems; and
    (4) speech-generating devices or any other assistive technology;
(b) the right to have such individual's communication method recognized and supported in schools, community residences, and public institutions;
(c) the right to speech therapy and communication support by duly licensed professionals without arbitrary restrictions;
(d) the right to have at least one trained staff member available in every facility or program to support individuals who require specialized communication assistance;
(e) the right to receive appropriate communication supports from trained staff, including direct support professionals (DSPs), educators, and healthcare providers; and
(f) the right to experience no restrictions or bans on an individual with disabilities' communication method.
This act shall take effect on the one hundred eightieth day after it shall have become law."
https://legislation.nysenate.gov/pdf/bills/2025/A7363B

2025 National Survey on Health and Disability

Earlier this year, AutCom received a letter from Justice Ender, who helps to administer the National Survey on Health and Disability (NSHD), through the Institute for Health and Disability Policy Studies at the University of Kansas. Ender noted that the survey "is one of the largest national surveys that asks people with disabilities about their experiences with health care access, housing, transportation, health insurance, community participation, and other life experiences."
The IHDPS requested our help "to reach people with disabilities and/or chronic health conditions to share their voice and experiences living as a person with a disability in the U.S" and noted that "The survey is open to anyone with a physical, mental, emotional or health condition who is over 18 years old – including those who may not identify as having a disability."

- The link to take the NSHD: https://kuhealthsurvey.org
- Website with recruitment materials (such as flyers, social media posts and videos) for download and sharing: https://ihdps.ku.edu/nshd-2025

They have not listed the final closing date for the survey.

Your Voice Matters: A Step-by-Step Guide to Contacting Congress About Autism and Disability Issues

By Maxfield Sparrow

You don’t have to be an expert. You don’t have to say it perfectly.

You just have to speak up—because the people making decisions about your life need to hear from you.

Whether you’re Autistic, disabled, a family member, or an ally, you have the right to contact your elected officials in Congress. You don’t need permission. You don’t have to do it in any one “right” way. You can do it in your own voice, in your own time, using the communication methods that work best for you.

Even if you’ve never done it before, this guide will walk you through how to contact your U.S. Senators and Representatives about the issues that matter most to our community—like disability rights, communication access, Medicaid, inclusive education, and banning harmful practices.

You don’t have to cover every issue. You don’t even have to write a full paragraph. One sentence, in your words, can be enough.

Step 1: Know Who Represents You in Congress

Each U.S. citizen has two Senators (who represent your entire state) and one Representative (who represents your district in the House).

You don’t need to know their names already.

To find them:
- 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

Click on each name to visit their official website.

Step 2: Find Their Contact Page

Each member of Congress has a “Contact” page on their official site. You can:
- Send an email using their web form
- Call their office (they list both Washington, D.C. and local numbers)
- Write a letter

- Request a meeting (for in-person or virtual conversation—more on that in our next issue!)

Look for links labeled “Contact,” “Email Me,” or “Get in Touch.”

Tip: You don’t have to use all methods. Choose what works best for you.

Step 3: What to Say

You don’t need fancy language or detailed facts. Just be:
- Honest
- Brief
- Clear that you are a constituent (someone who lives in their state or district)

Here’s a simple script you can copy and adapt:

“Hi, my name is [your name], and I live in [your city or ZIP code]. I’m writing to ask [Representative/Senator] [Name] to support [or oppose] [a policy or issue]. This matters to me because [optional: your reason]. Thank you for your time.”

If you’re Autistic or disabled, saying so is powerful. It reminds your elected official who is directly affected by these decisions.

You don’t have to tell your whole story. But if you want to include a sentence about how a bill or issue impacts your life, you can.

Step 4: Calling Instead?

Many people are scared to call. That’s okay. You don’t have to answer questions. You can write down what you want to say and read it, or even just leave a voicemail.

Example:
“Hi, my name is [your first name], and I live in [your ZIP code]. I want to ask [Senator/Representative Name] to vote against any bill that cuts Medicaid or harms people with disabilities. Thank you.”
That’s enough. You can hang up after that.

Step 5: It Counts

You may not get a personal response—but your message gets logged. Congressional offices count every message of support or opposition they receive.

It takes only a few minutes to help show how many people care. When enough constituents speak up, it changes how members of Congress think, vote, and prioritize. If you write a letter by mail, you might even get a physical letter back. (I know people who collect them!)

Common Autism and Disability Topics You Can Write About
These are just a few examples of issues Congress works on that affect our community. You can choose one or two that matter to you—or bring up something else entirely.

Health Care & Medicaid
- Protecting Medicaid Home and Community-Based Services (HCBS)
- Preventing cuts to SSI, SSDI, or disability-related benefits
- Supporting access to AAC devices and communication support

Education & Employment
- Fully funding IDEA (special education law)
- Ending subminimum wages for disabled workers
- Promoting inclusive classrooms and communication access

Civil Rights & Safety
- Strengthening the Americans with Disabilities Act (ADA)
- Ending abusive practices like electric shock devices and restraint/seclusion
- Protecting the rights of Autistic people to make their own decisions

Research & Representation
- Funding neurodiversity-informed autism research (not cure-based)
- Including Autistic people in policy decisions
- Supporting mental health and suicide prevention programs that include Autistic voices

Tips for Neurodivergent Communicators

You can contact Congress in the way that works best for your communication style.

Some people:
- Use AAC to write or speak their message
- Record a message and play it over the phone
- Ask a friend to help send an email or letter
- Script or bullet-point what they want to say

There's no “wrong” way to be heard.

You Have the Right

Your members of Congress work for you. They need to hear from the people they represent—not just lobbyists or political insiders.

Whether you speak with your voice, your hands, your device, or your keyboard, your words matter.

Let them know what's important to the Autistic and disability community. Let them know you're paying attention. Let them know we're here—and we're not going away.

Understanding the Sensory and Movement Dilemma: The Autism Paradox -- Webinar Recording Now Available for Viewing

AutCom Presents:

FREE ONLINE WEBINAR:
UNDERSTANDING THE SENSORY AND MOVEMENT DILEMMA: THE AUTISM PARADOX

SATURDAY, APRIL 5, 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 – 10:00am PT

Moderated by
Maxfield Sparrow,
Autistic writer,
scholar-activist

Sujit Kurup

Jamie Burke

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, Understanding the Sensory and Movement Dilemma: The Autism Paradox, is now available for viewing free. This free online webinar aired on April 5, 2025. AutCom board members, Sujit Kurup and Jamie Burke, presented on how the sensory and movement issues of autism affect them and what therapies and methods they use to help integrate their senses and gain more control over how their bodies move.

The webinar video recording is available at the following link with corrected captioning and 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://youtu.be/ojUEWKhzETg?si=r_i5jPegmWUXrHG5

Letter from Dan Bergman

To all my sisters and brothers who spell or type—

Let's come together on July 19th to show the world what we can do and have fun doing it. Here's what I mean. I and about forty other people, actors, technicians and cinema craftspeople, are making Pointing Fingers the first full length fiction feature film written by a nonspeaker who types as I am typing this now, tapping letters on an iPad one at a time. The movie is about nonspeakers who spell, and all the nonspeakers are played by nonspeakers with autism.

In the story, which represents my greatest hopes and fears, two nonspeakers meet, fall in love and move into an apartment together with an aide who helps them with everything and acts as their communication partner. Unfortunately, their aide has a past they didn't know about, and one morning they wake up to find that she's been murdered. Not knowing what else to do, they carry the body into the street, and get arrested for a crime they had nothing to do with.

Here's where you come in. I want to show the world that for all our IEPs and individual differences and despite all the help we need, we are and can be a community. So this is what I dreamed up: A whole bunch of spellers and typers show up to demonstrate at the courthouse where the central characters are being arraigned. They wear t-shirts and have signs. It feels like a festive occasion. Then to make the point that community is essential, the central characters come out on bail discouraged by the ordeal they are going through. They tell their supporters that it's just too hard. They are giving up on living independently. The good mood in the demonstration vanishes and the supporters' disappointment is so great that my central characters reaffirm their commitment to forging their own lives and, with their new friends they figure out who the murderer is and bring him to justice.

The story is fiction but the cause is real. The signs will say things like "We have the right NOT to remain silent." You can come up with your own idea and our prop person will make the sign for you.

Have you always wanted to be in a movie? Me neither. I started out wanting to write scripts because I'm so used to hearing other people say aloud what I type. I wasn't going to act in the movie, but then I realized I wanted to see myself in these imaginary situations. The great thing about fiction is that unlike a documentary we can represent realities that don't exist yet but should.

Years ago, I and some of the people making Pointing Fingers had the pleasure of working on my friend Elizabeth Bonker's music video "I Am in Here." If you haven't seen it, check it out. It's an inspiring example of how our community can mobilize to make an important statement by bringing a work of art to life.
https://www.youtube.com/watch?v=ZA4rVy6vx-E

So come share the climactic moment in this astonishing and groundbreaking film. We can look back at it in ten years when typing is well understood and as completely accepted as Braille and ASL.

Thank you — Dan Bergmann

When: July 19, 2025, 10 AM

Duration: about 3 hours.

Where: Outside the courthouse in Lawrence, MA

Pay: Pointing Fingers is an extremely low-budget feature film, supported by (so far) 2 foundations and 75 individual donors. Nevertheless

You will get paid. It's important. Each nonspeaker participant will be paid $100, each communication partner or caregiver will be paid $50. You will each also get $20 toward lunch, and we will arrange or pay for your parking.

A few nonspeakers who will participate in other parts of the film will get $249/day for their participation. We will come to your house or place of choice for a few hours later in the summer to record your participation as characters who participate online. Let us know if you are interested in one of these more substantial roles.

If you want to participate please get in touch with Dan Bergmann: uffizi2004@icloud.com

Or call Michael Bergmann, director and producer at 917-273-3438.

If you have difficulty with transportation, please let us know and we will try to help.

We Want Your Letters, Poems, Articles, Book Reviews...

We know that AutCom members have a lot to share. We would love to receive your letters, articles, poems, book reviews, or announcements of events that would be of interest to AutCom. We are especially interested in hearing from autistic members. Please let us know if you have something you would like to share in future newsletters.

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).

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 Autism National Committee 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

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