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The Communicator

A publication of the Autism National Committee

Introduction

We hope you enjoy the Spring issue of *The Communicator*. In the first article, *Chosen, Not Assigned*, Max Sparrow challenges the use of the pervasive puzzle symbol to represent autism - a symbol unfortunately created without participation of autistic people. Jamie Burke and Nancy Weiss both address issues related to our organization's long-term mission of supporting human rights. Jaime describes his political efforts in defending the right to communicate in his home state of New York. In her article, Nancy requests support for her ongoing work in stopping the abusive practices at the Judge Rotenberg Center. AutCom continues to produce some incredible webinars. We provide a link to our most recent one, in which participants question mental age theory. AutCom Board member Yasmin Arshad shared a poem in that webinar entitled *My Outrage*. That poem appears in this issue. The Communicator also contains a description of a remarkable new video "Pointing Fingers," starring Autcom Board Member Dan Bergmann. Congratulations Dan! As always, the newsletter includes resources that we hope you will find useful. Have a great Spring!

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Chosen, Not Assigned

by Maxfield Sparrow

The puzzle piece was never ours. Here's the story of the symbols that are.

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A respected friend and colleague recently said he hadn't been aware of many of the symbols for autism and specifically was not sure about the infinity symbol. "The only thing I know for sure about myself is that I'm finite," he said.

Of course, his view was valid and his words were true. But the infinity symbol isn't about any one person. It symbolizes the infinite ways there are to be Autistic. To understand why that matters, we need to go back to the beginning.

The puzzle piece symbol was created in 1963 by Gerald Gasson, a parent and board member of the National Autistic Society in London. The original logo featured a puzzle piece with an image of a weeping child inside it. It was not designed by Autistic people. It was designed by and for the people around us, and it communicated their distress, not our humanity.

The National Autistic Society's own Helen Allison explained the thinking behind it plainly: "The puzzle piece is so effective because it tells us something about autism: our children are handicapped by a puzzling condition. This isolates them from normal human contact and therefore they do not 'fit in'. The suggestion of a weeping child is a reminder that autistic people do indeed suffer from their handicap."

That framing of autism as a puzzling burden and autistic people as isolated and suffering shaped decades of advocacy about us. The symbol spread, the crying child was eventually dropped from the image. But later versions showed a child with a puzzle-piece-shaped hole missing from his head. Over time, many organizations adopted their own versions of the puzzle piece symbol. The common denominator was the underlying message of Autistic people as mysterious and lacking in some vital piece of brain or identity.

In 2011, Virginia Tech English professor Paul Heilker and Autistic scholar M. Remi Yergeau wrote in *College English* that puzzle pieces "symbolize so much of what is wrong with popular autism discourse — representing autistic people as puzzling, mysterious, less-than-human entities who are 'short a few cognitive pieces,' who are utterly self-contained, disconnected, and [who] need to 'fit in'."

It is worth pausing here to say clearly: many people have used this symbol out of genuine love. Parents have worn puzzle piece clothing and jewelry and even tattooed puzzle pieces on their bodies to display their pride in and devotion to their children. That love is not in question. At the same time, love deserves a symbol worthy of it. There are many symbols that reflect who Autistic people actually are, rather than how frightening

and mysterious we seemed to those who first tried to make sense of us. There are symbols that were created by and for Autistic people, not without us.

The National Autistic Society, to its credit, no longer uses the puzzle piece. Their current logo is a flowing symbol rendered in a rainbow spectrum of colors. Even those who first created the puzzle piece have recognized what the Autistic community has known for years: we deserve something better. And we have not waited for permission to find it: Autistic people have searched for symbols that reflect who we actually are. Several have gained genuine traction within the community, not because any organization imposed them from above, but because they resonated from the inside out.

The dandelion began within the Autistic community and was adopted by Specialisterne, a Danish social enterprise founded in 2004 to create employment for neurodivergent people. Their reasoning cuts right to the heart of what it means to be Autistic in a world not designed for us: a dandelion in an unwelcoming environment is a weed, but in an environment that values it, it becomes an herb: nutritious, medicinal, and useful. The symbol asks not what is wrong with the person, but what is wrong with the environment. The giraffe has a stranger and more joyful origin. In *The ABCs of Autism Acceptance*, I documented how the giraffe emerged when Autistic people spoke up against a song that used defamatory language about us. Rather than responding with anger alone, the community did something characteristically Autistic: they turned the offensive into a joke, using laughter and collective joy as tools against ignorance. The giraffe was adopted rapidly and organically as a symbol of Autistic power, Autistic humor, and Autistic community.

The same defiant spirit animated the Red Instead movement. I have never been comfortable with blue as our color. It was chosen because, at the time, autism was believed to affect boys at far higher rates than girls, and we now understand that was diagnostic bias, not biology. Girls, women, and nonbinary people were being missed and misdiagnosed, and the color chosen to represent autism reflected that invisible erasure. In 2015, Autistic activist Alanna Rose Whitney launched #WalkInRed, later renamed #RedInstead to be more inclusive of wheelchair users. Red was chosen by the community, for the community, and for all of us this time.

Most recently, Aaron Jepson, an Autistic writer and Speller, has proposed the acorn. His reasoning is beautiful: the acorn has a hard shell, but all the potential of an enormous tree lives within it. The shell is not a flaw. It is protection for something that, given the right conditions, will grow large and magnificent. Jepson's image challenges the puzzle piece's assumption of incompleteness and replaces it with an image of latent, waiting wholeness.

Each of these symbols was chosen, not assigned. Each says something true about Autistic experience. Each deserves a place in our community's visual language.

Of all these symbols, the infinity symbol has held the longest and strongest, and comes closest to uniting the whole community. Unlike symbols that came from outside the

community, the infinity symbol emerged from within the Autistic community and has only grown stronger over time.

It began with Aspies for Freedom (AFF), an Autistic-led advocacy group founded in June 2004 by Amy and Gwen Nelson. In 2005, AFF launched the first Autistic Pride Day and introduced the rainbow infinity symbol as its emblem. As Gwen Nelson explained at the time: “A spectrum — for the Autistic spectrum. And forever — as in ‘Autistic forever.’”

The rainbow infinity was chosen deliberately. Its spectrum of colors represents the vast diversity within the Autistic community. Over time, the rainbow infinity has come to represent the broader neurodivergent community as well, with all the many ways human minds can work differently. For autism specifically, many advocates use the gold infinity, a variation that carries its own quiet brilliance: gold for Au, the chemical symbol for the element gold, which also happens to be the first two letters of autism.

The symbol spread organically, carried by Autistic people themselves rather than pushed by any institution or awareness campaign. Today, organizations and local governments across Scotland have adopted it, flying the infinity flag to mark Autism Acceptance Week. South Lanarkshire Council, for instance, has done so for four consecutive years.

The infinity symbol has not been without challenges. Some have tried to attach it to purposes and organizations that contradict its original spirit. But it has proven resilient. It belongs to us in a way that is difficult to sever, because it did not come from those attempting to define us. It came from Autistic people, ourselves.

The puzzle piece was never ours. It was created about us, at a time when no one thought to ask us, because no one believed we were capable of speaking for ourselves. The infinity symbol, the giraffe, the acorn, the color red: these we chose for ourselves. That difference matters enormously. A symbol imposed from outside, however well-intentioned, carries the values and fears of the people who made it. A symbol chosen from within carries something else entirely: the lived understanding of people who know what it means to be Autistic in a world that was not built with us in mind.

These symbols do not have to compete with one another. The giraffe and the acorn and the infinity symbol can all be true at once, each saying something different and necessary about who we are. What matters is not which symbol any of us chooses, but that we are the ones doing the choosing.

I think again about my colleague who wasn’t sure about the infinity symbol. “The only thing I know for sure about myself,” he said, “is that I’m finite.” It’s a fair point, and a very human one. But the infinity symbol was never asking any one person to be infinite. It was asking the world to recognize that there is an endless diversity of Autistic experience. And his particular, finite, irreplaceable way of being Autistic deserves full recognition and acceptance, just as it is.

I told him this and he changed his mind, because once it's clear what the symbol is actually saying, it makes sense. Autistic people have only been gathering together under that diagnostic name for a few decades, but already we have built a rich culture and history. Symbols are more than logos or brand identities. Our symbols are visual reminders of our beauty, our diversity, and the power of Autistic lives.

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Maxfield Sparrow is a board member of AutCom, a peer support facilitator with AANE, an author of several books about autism, and editor of the anthology _Spectrums: Autistic Transgender People in Their Own Words_ (Jessica Kingsley Publishers, 2020). Sparrow discusses adult autistic meltdowns at www.unstrangemind.com

Update on New York State Communication Bill of Rights

by Jamie Burke

This is fundamentally important and is of immense concern to people who use an alternative method of communication. I know this is presently being pursued here in my home state, New York, but I am dearly encouraging others to engage this in their own home states. At times we are required to provide our own voice to the representatives who vote and it can bring a feeling of anxiety, hoping you feel listened to and opinions valued thoughtfully. My fellow AutCom members, Sujit, Kani and Kashi and I met with two senior staff members from 2 of our local Senators. We relayed how paramount it is to hear of our life journeys and to understand that we would not have accomplished what we have worked so sincerely hard on, and we would not have succeeded without the ability to communicate, connect and realize our sincere hopes. If you are interested to learn about this, please look below. We want to encourage New York people to seek out and inform their representatives how vital this Bill is, and to vote YES on the original bill S7792B with no amendments.

New York State Communication Bill of Rights
for Disabled Individuals S7792b.
NY State Senate Bill 2025-S7792B

Update on Judge Rotenberg Center and a Request for Help from Nancy Weiss

AutCom recently received a letter from Nancy Weiss providing important information which she asked us to share regarding the Judge Rotenberg Center in Massachusetts. With her permission, we are publishing the entire letter, which has updates and also a request for some help, insights or connections. We encourage you to keep up with these efforts and to help as you can to stop the pain, harm, and trauma.

Some unfortunate news to share … last month the Massachusetts House of Representatives relegated H.245, the bill that would have outlawed the use of all aversive procedures in Massachusetts, to a “study order”. On the face, this means that the committee on Children, Families and Persons with Disabilities is being asked to further investigate these issues before the bill can be reconsidered. However, in practice this often means that the bill has been killed. This has been the case with a number of similar bills related to outlawing electric shock or, more generally, aversives that Massachusetts has tried to pass over many years. There is some possibility that a similar bill will be proposed; but for now, H.245 is not moving forward.

On the ‘still may be good news’ front, the FDA’s current unified agenda continues to predict that the ban on electrical stimulation devices used for self-injurious or aggressive behavior will be finalized in May of this year. This is not a commitment; Unified Agendas may be thought of more like ‘to do’ lists, representing what is planned, but not providing

guarantees. While Unified Agendas are often aspirational regarding dates and timelines, it is somewhat reassuring that this issue remains on the FDA's plan. Though I of course continue to question why, when the comment period closed in May 2024, this has dragged on as long as it has.

Now for a couple of requests for help …. I want to learn more about how school districts and states determine which children (in their view) need out-of-state residential treatment and how decisions are made regarding the facility to which children are sent. If you know someone in your state who is involved in these processes/decisions at any level (local or state), I'd love an email introduction so I can chat with them for a few minutes and understand more about how this works state-to-state.

Additionally, I am interested in talking with provider agencies that serve people with more significant behavioral needs in more than one state. I know that there are states that are easier to work with, have better funding mechanisms, etc. I want to learn more about those agencies that work within New York State or have considered (or would consider) working in NY. I am working with them to understand whether there are there changes the state could make to structure things to be more inviting to multi-state providers who serve people with behavioral challenges. If you represent an agency (or know someone who does) that offers residential services in NY or has considered doing so, I would very much appreciate an email introduction so I can learn more about this issue.

Many thanks to each of you for any connections you can offer and for continuing to keep this issue as one that is important to you.

Best,

Nancy Weiss

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We applaud . . .

The ongoing urgently important work of advocates for communication rights and for access to communication methods of their own choice in New York for The Communication Bill of Rights 9S7792b (original bill with no amendments) and in Ohio for similar upcoming legislation. Communicating the urgency and absolutely necessity of access to communication so that legislators understand and provide support is critically important, and advocates have done and continue to do an outstanding job in this work. We encourage all to watch for opportunities to join and support this important advocacy across the nation.

Resources

Articles

Autistic masking may have evolved as a survival strategy but at what cost? Masking as an Evolutionary Advantage. Hari Srinivasan, Giving Voice, Psychology Today. January 9, 2026.
https://www.psychologytoday.com/us/blog/giving-voice/202506/masking-as-an-evolutionary-advantage

Why Sensory Overload Isn't About "Too Much". A different view of sensory effort in autism and ADHD. Hari Srinivasan, Giving Voice, Psychology Today. January 10, 2026.
https://www.psychologytoday.com/us/blog/giving-voice/202601/why-sensory-overload-isnt-about-too-much

Words That Wound: Why Functioning Labels Harm Autistic People. On the ethics of sub-grouping and functioning labels. Helen Edgar, April 5, 2026. "It is not labels but the presence or absence of understanding, support, and respect that determines whether autonomy is upheld or denied for Autistic people. Functioning labels not only misrepresent us, they actively shape what happens to us and harm us."
https://news.neurohubcommunity.org/p/words-that-wound-why-functioning

Books

What We Are by Graciela Lotharius. Paper chapbook / 2025 / 35 pages. "Graciela Lotharius is a fierce believer in hope and justice. She works in numerous ways to shape her changemaking thoughts into transformative poems that she hopes will be life-giving to others."
https://www.unrestrictedinterest.com/reading/p/what-we-are-by-graciela-lotharius

Upward Bound by Woody Brown. "Chaos outside neutralises the chaos inside," … "I was in the pit of despair." Non-speaking autistic novelist Woody Brown on his journey from write-off to writer. Simon Hattenstone, The Guardian. "As a child, Brown was underestimated, infantilised and dismissed by specialists and teachers. Now 28, he has written an acclaimed debut novel set in an adult day care centre that gives people like him a voice." March 28, 2026.
https://www.theguardian.com/books/2026/mar/28/i-was-in-the-pit-of-despair-non-speaking-autistic-novelist-woody-brown-on-his-journey-from-write-off-to-writer?

Video, film

How to Boil Water the EASY Way. silentmaiow. A.M. Baggs. “A funny-but-serious description of how to boil water, from someone who really DOES find it at least this difficult in real life. While it's presented humorously, this is about something that can be a real problem for autistic people among others, especially if we're either presumed capable of this because of our academic abilities or presumed academically incapable because of our trouble with this sort of stuff.”
https://youtu.be/9fUi1EYq6Rs

Note: This one is by the late A.M. Baggs (Mel) from 18 years ago, but it has been getting some attention lately, and it is worth a second look—or a first look if you have not seen it before now.

AutCom is sponsoring the following screening:

Pointing Fingers: The **first** feature film in cinema history in which all the roles of autistic characters are performed by autistic people. This is revolutionary filmmaking! It tells a story that has never been told, in the voices of the people who live it. A young couple in **love**. A murder **mystery**. The silence of **autism**.

Starring: Emily Faith Grodin and Dan Bergmann, autistic self-advocates who use AAC to communicate. With performances from more than 20 people who use AAC to communicate

When: Saturday, May 9, 2026. Doors open 12:30. Screening begins 12:45. Q&A with the filmmakers to follow.

Where: Fine Arts Theater, 19 Summer Street, Maynard, Massachusetts 01754. The Fine Arts Theater is staffed by disabled people. Admission by sliding scale. Please come fragrance free.

The Right to Grow Up: Mental Age Theory

The recording is ready! Watch it again or watch it for the first time and share it.

We are very pleased to announce that the recording of our February 28, 2026 webinar, "The Right to Grow Up: Mental Age Theory", is ready and on our website and YouTube https://autcom.org/events/past/autcom-webinar-february-2026/ or https://www.youtube.com/watch?v=rBR9QElTxPY

AutCom Vice President Ivanova Smith presented about their lived experiences and the importance of the Right to Grow Up, along with the harms of using mental age theory. AutCom Board member Maxfield Sparrow moderated a panel of autistic adults who share their lived experiences: Dan Bergmann, Ali Burris, and Yasmin Arshad. A question-and-answer session with the audience followed.

Ivanova Smith is a disability advocate and Community Collaboration Program Manager in Washington State and is happily married with two children.

In the webinar, Yasmin Arshad shared her poem, My Outrage, which is included in this newsletter.

My Outrage.

When I was dearly wishing it
My family told me I'd never drive.
When I was sadly missing it
My mother told me I'd never parent.
When I was really feeling it
My father called me dumb.
When I really gave my love
My teachers only got me mad.
People have never understood
The special feelings I may have.
Only believe in me
And I will grow up too!

- 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.

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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 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 <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: <u>www.autcom.org</u>.

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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