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THE COMMUNICATOR

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Introduction

In this issue we start by celebrating the memory of AutCom co-founder and past president, Pat Amos. Fittingly, given Pat's fierce commitment to the rights of autistics, we address several topics related to human rights, The first is *Supported Decision-Making*, an exciting alternative to guardianship and conservatorship that protects the right of individuals to be the final decider in issues regarding their own lives. Board member Maxwell Sparrow addresses some of the negative consequences for human rights that can arise from the use of the term "profound autism," including institutionalization and pushing families toward guardianship. Max has also written two reviews - one of the "Neurotypical Cafe" and another of the film "The Fish Don't Care When it Rains." This important film documents the horrific experiences of one woman who was tortured at the Judge Rotenberg Center in the name of therapy. AutCom is proud to be a co-sponsor of this film. As always, we share new developments in the "New and Exciting" section. We end with a beautiful poem from Dan Bergman. We encourage others to share their poetry and other writing as we continue our effort to prove the Health and Human Services Secretary incorrect when he says that autistics will never write poetry.

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In Memoriam - Pat Amos
Co-Founder and Past President of AutCom



Pat Amos was one of the co-founders of the Autism National Committee, past-president, conference chair, and publications editor. Pat was an incredibly tenacious parent and advocate who thrived on challenging both previously established assumptions about autism and the individuals who perpetuated negative stereotypes, outdated perceptions, and torture masquerading as therapy. Her absolute commitment to positive approaches and inclusion in both school and community inspired many of us.

A review of her CV leaves one wondering how she had time for all she accomplished - both as an organizer and as an advocate for human rights and inclusion. Pat was a board member of the Pennsylvania Education for All Coalition, Networks and Training, Inc., the Alliance to Prevent Restraint, Aversive Interventions, and Seclusion, TASH, Family Alliance to Stop Abuse anjd Neglect, Autism Support and Advocacy in Pennsylvania (and a co-founder), and the Autism Society of Greater Philadelphia. Other organizations with whom Pat shared her expertise included the Coalition of Inclusion Advocates, Autism Living and Working, Inc., Hilltop School Strategic Planning Team, Children Injured by Restraint and Aversives, the Occupational Therapy Program at Philadelphia University, and the Pennsylvania Developmental Disabilities Planning Council. In addition to her work with these organizations, Pat worked as an inclusion specialist both privately and for Youth Advocate Programs.

Pat wrote and spoke extensively. Among the many topics she addressed were: movement differences and sensori-motor issues in autism, how people learn (moving beyond behaviorism), self-determination, preventing aversives and restraints, inclusion in school and community, positive approaches, anxiety and autism, a critique of the "marketing" of autism, transition to adulthood, employment for autistics, and the myth of IQ and mental age.

Pat was the recipient of a number of awards including the First Annual Herb Lovett Memorial Award (1998), the TASH Positive Approaches Award (2003), and the Youth Advocate Programs Leadership Award (2010).

Pat's Pennsylvania colleague Joe Leonard shared the following remembrance:

> Pat’s intellectual leadership in the disability/autism community, first in Pennsylvania and then nationally, introduced professionals and families to cutting edge understandings of

> inclusion in society of people with disabilities. Specifically related to autism, Pat leveraged her credibility in the field to bring to Pennsylvania leading edge thinkers and practitioners in the 80s-90s, well before autism was recognized by the education or human service systems in the state.
>
> As an organizer, Pat gave intellectual leadership to Autism Support and Advocacy in Pennsylvania (ASAP) at a critical time when state agencies were looking for input from credible sources in the autism community. One result was for the first time the inclusion of autism as a category, separate from mental retardation, in the Pennsylvania Department of Education regulations, bolstering the few existing educational programs for individuals on the spectrum, and leading to an expansion of programs in public schools as well as greater inclusion with supports in regular classrooms. Pat's work in the founding and leadership of the national advocacy organization, AUTCOM, brought her gifts to country-wide efforts that for the first time included individuals on the spectrum as leaders and spokespeople.
>
> The other marvelous impact of Pat's presence in the autism community was her humor! Her skill in satire skewered any number of deserving frauds, scams and self-proclaimed gurus, seeking to "make a buck off autism" or perpetuate obsolete concepts and "treatments" for it. Her contribution to maintaining morale among all of us involved with parenting, advocating, searching, organizing was monumental.

Diana Deri said that Pat Amos was a life-changing part her and her son John's life. She said that Pat was a national treasure of the Autism support community and credits her for helping her son get into college. Diana asks everyone to pray for for Pat's surviving husband Phil, and her children Dan, Marin, Nick, and Aiden. Diana is lost for words over how wonderful Pat is, and she asks everyone to *pray* for those who have experienced the loss during this time.

Martha Leary said of Pat:

> When I first met Pat Amos I thought she might be a graduate student. No bigger than a teen, Pat had a brilliant mind that informed her work and advocacy for people with disabilities. Pat was a caring mother. She had a great capacity for empathy and clearly understood what it felt like to be different. She noticed where the world was unfair and worked hard to change it, creating new ways to support accommodation. She taught me that often the best way to help is by inspiring others to become great supporters and champions. It was also so much fun to be with her. I miss her and am sad that the world has lost one so precious.

Alan Kurtz recalls the time in the early 90s when he did a workshop in Pennsylvania on facilitated communication. The workshop organizer, who was big in the Autism Society of America, hired security because he thought Pat's organization, ASAP, would disrupt the workshop. Pat and Alan

later had a good laugh over that! Although there was no foundation for the organizer's concerns, Pat was definitely pleased to have gotten into his head!

Of course, Pat Amos was criticized by many in the autism establishment. That is not surprising given her critique of existing systems. As part of that critique Pat established AutCom's Distinguished Disservice Award and identified many deserving recipients. One recipient later referred to her as an "advo-zealot." Far from being insulted, Pat cherished the sobriquet.

Sandra McClennan dug into her archives and found the following song lyrics that Pat wrote celebrating the term that had been applied to her.

ADVOZEALOTS' ANTHEM

(by Pat Amos to the tune of "My Darling Clementine")

Advozealots, advozealots,
Advozealots, gather round.
We are here to stay forever,
As we claim the higher ground.

No more pity! It's not pretty.
We shall evermore reflect
On supports and accommodations,
And on mutual respect.

Fare thee well to segregation,
And to weird technology,
Fare thee well to "special places"
Filled with boredom and ennui.

Communication, that's the answer,
Not behavioral control.
Our agenda's non-electric,
It's the power of the soul.

Published by the
Autism Liberation Front

Perhaps the best tribute we can make to Pat Amos' memory is to continue our work as advozealots in the struggle for autism liberation and the celebration of neurodiversity.

Supported Decision-Making: An Alternative to Guardianship

What is Supported Decision-Making?

Supported Decision-Making (SDM) is a legal alternative to guardianship designed to provide people with the supports they need to make decisions about their own lives. A person using supported decision-making is often called "the decider." The decider:

- Indicates what decisions they will make without support;
- Decides in what areas they may need support in making decisions;
- Chooses one or more trusted people (supporters) to help them make major decisions about their own lives (They may choose different people to help them in various areas. For example, they might choose one supporter to help them with medical decisions and another to support them with banking and money management.)
- Determines what kind of support they will receive (For example, Wisconsin's Supported Decision-Making form lists various types of support including: (a) helping access, collect, or obtain information, including records, relevant to a decision; (b) helping the decider understand options, (c) helping the decider communicate decisions to appropriate persons; and (d) helping the decider access appropriate records including protected health information;
- Develops with others a formal Supported Decision-Making Agreement (SDMA); and
- Has the **final say** in all decisions.

The SDMA is a legally binding document that identifies the person's supporters, the role of each supporter, and how supporters will help. The SDMA is filled out and signed by the decider and supporters. The agreement may be shared with medical professionals, schools, financial institutions, and others who might otherwise require the approval of a guardian.

What Kind of Decisions are Made Using SDM?

- Where you will live;
- What kind of supports you might receive and who will provide those supports;
- The kind of job you want;
- What kind of education you want to pursue;
- Financial decisions and how to manage your money;
- Healthcare decisions;
- Issues related to your personal and social life including what you do with friends or family, community activities, or organizations to join; and
- Transportation, including how you get to work, social or recreational activities, or medical appointments.

Why do we need an Alternative to Guardianship?

Adult guardianship occurs when a court takes away a person's right to make their own decisions. It allows a person appointed by a court to make those decisions for the person. This is inconsistent with both the principle of self-determination and democratic ideals.

Legal Status of Supported Decision-Making

At least forty states and the District of Columbia have passed laws supporting SDM. Eighteen states have gone as far as requiring probate courts to consider SDM prior to appointing a guardian or conservator. Four states have passed legislation allowing it as an accommodation for healthcare decisions. Nine have required its use in transition planning and transfer of rights decisions.

In all cases, the person using SDM retains their legal right to make final decisions. This is true even if supporters or other third parties disagree. In states where SDM is supported, SDMAs are generally regarded as a legally binding. For more information on the legal status of SDM in various states go to https://supporteddecisions.org/resources-on-sdm/state-supported-decision-making-laws-and-court-decisions/

SDM Within a Broader System of Supports for Communication and Self-Determination

To effectively implement SDM, the decider needs to be able to communicate their choices. Minimally, they need to indicate what decisions they want to make on their own, who their supporters will be, how those decisions will be made, and whether they agree with the SDMA. This highlights the need to do everything possible to support a person's ability to communicate significant choices - whether they do so through speech, writing, spelling, or with other AAC strategies. It also highlights the need to provide autistics with opportunities to use whatever communication they have to make meaningful choices throughout their lives.

Unfortunately, many autistics have been provided few opportunities to make meaningful choices. Making big decisions about one's life can be difficult when your previous choices have been limited to options such what to have for a snack, what shirt to wear, or what to watch on television. Experience with self-determination can go a long way in preparing a person to make big decisions about their lives. *Self-determination* essentially means setting your own goals, determining how you will reach those goals, monitoring your progress, and making appropriate changes to your plans. Self-determination goes well beyond simple choice-making. It also improves with practice. We know that both experience with self-determination and its incorporation into educational programs are strong predictors of post-school success. Unfortunately, autistic individuals seldom experience significant opportunities to enhance self-determination in school. Many transition IEPs fail to even mention self-determination. To help

people prepare for using SDM, self-determination should be supported - at home, at school, and ultimately in the workplace.

SDM provides an opportunity for autistics and others to move beyond the serious limitations of guardianship. It is a valuable tool people can use in making important decisions about their own lives. It undoubtedly will be most effective, however, if it is embedded within larger systems that include effective lifetime supports for communication and self-determination.

Supported Decision-Making Resources

General Resources.

ACLU Supported Decision-Making Library: https://www.aclu.org/documents/supported-decision-making-resource-library

Center for Public Representation: CPR Supported Decision-Making Library: https://supporteddecisions.org/resources-on-sdm/

Center for Public Representation: *Legal Capacity: Supported Decision-Making. https://www.centerforpublicrep.org/initiative/supported-decision-making/*

Disability Rights Maine: Alternatives to Guardianship and Supported Decision-Making: https://drme.org/resources/know-your-rights/alternatives-to-guardianship-supported-decision-making/

Honoring Choices Massachusetts: *Supported Decision-Making in Massachusetts:* https://www.honoringchoicesmass.com/supported-decision-making/

National Resource Center for Supported Decision-Making: https://supporteddecisionmaking.org/

Summary Paper: ASAN's Invitational Summit on Supported Decision Making and the Transition into the Community: https://autisticadvocacy.org/wp-content/uploads/2017/05/OSF-Summit-Summary-Paper.pdf

ASAN's: *The Right to Make Choices: International Laws and Decision-Making by People with Disabilities: https://autisticadvocacy.org/wp-content/uploads/2016/02/Easy-Read-OSF-For-Families-v3.pdf*

US Administration for Community Living: *Supported Decision Making Program*: https://acl.gov/programs/consumer-control/supported-decision-making-program

Supported Decision-Making Tools.

Sample Supported Decision-Making Agreements: https://supporteddecisionmaking.org/wp-content/uploads/2022/10/sample-supported-decision-making-model-agreements.pdf

ACLU Supported Decision-Making Agreement: https://www.aclu.org/documents/aclu-supported-decision-making-agreement

National Resource Center for Supported Decision-Making: *Supported Decision-Making Model Agreements:* https://www.aclu.org/documents/aclu-supported-decision-making-agreement

State of Wisconsin, Department of Health Services: *Supported Decision-Making Agreement.* https://www.dhs.wisconsin.gov/forms/f02377.pdf

National Resource Center for Supported Decision-Making: Supported Decision-Making Brainstorming Guide: https://supporteddecisionmaking.org/resource_library/supported-decision-making-brainstorming-guide/

Delaware Supported Decision-Making Agreement https://supporteddecisionmaking.org/wp-content/uploads/2022/10/delaware-sdm-agreement.pdf

District of Columbia Supported Decision-Making Agreement: https://supporteddecisionmaking.org/wp-content/uploads/2022/10/DC-SDMA-Instruction-Form.pdf

Disability Rights New Hampshire: Supported Decision-Making Toolkit: https://drcnh.org/know-your-rights/supported-decision-making-toolkit/

Michigan Department of Health and Human Services: Supported Decision-Making Toolkit: https://www.michigan.gov/mdhhs/keep-mi-healthy/mentalhealth/developmentaldisability/supported-decision-making/sdm-toolkit

I DECIDE KANSAS: *Use SDM:* https://www.idecidekansas.org/use-sdm

California State Council on Developmental Disabilities*: Supported Decision Making Discovery Tool*: https://scdd.ca.gov/sdm-tap-resources/who-do-i-want-to-support-me-supported-decision-making-discovery-tool/

Disability Rights Texas: *Supported Decision-Making Agreement Tool:* https://disabilityrightstx.org/en/supported-decision-making-agreement-tool/

Watch for our next webinar! Coming soon!

AutCom is busy planning its next webinar, which will be on the topic of Supported Decision-Making. We are assembling a panel for discussion and working out a date and time.

Watch our social media (Facebook, LinkedIn, and Instagram) for more information in the coming weeks. We hope you will be there!

To introduce the topic here, we have a short video to share. In this video, using avatars for the speakers, **AutCom Vice President Ivanova Smith** interviews David Lord, from Disability Rights Washington about Supported Decision Making.

> **Conversations with Ivanova: Supported Decision Making**
> "What is Supported Decision Making and how is it different from guardianship? Ivanova Smith interviews David Lord from Disability Rights Washington to find out how Supported Decision Making works." (4:09 with captions)
> https://youtu.be/IrCg9r4qSJU?is=FflkDMRI1U_gKSeQ

Talking About Us:
What the Term "Profound Autism" Is Being Hired to Do

By Maxfield Sparrow

My mind is screaming, 'Don't touch house!'

— Ido Kedar, nonspeaking Autistic author, writing at seventeen on his blog *Ido in Autismland* (February 16, 2014)

The Question the Label Pretends to Answer

Ido Kedar was a boy in a therapy room, pointing at flashcards. He knew the right card. His hand went to the wrong one anyway. Years later he wrote down what he would have told his instructors if he could have: that his mistakes on those drills were being read as proof he didn't understand, so the lessons stayed babyish year after year. That's what it looks like when a system decides who someone is before it asks them.

A new term has entered the conversation. “Profound autism” now turns up in research protocols, in federal planning documents, and in conversations among people I respect. Before I argue about it, I want to ask what work it's being hired to do. A label is a tool. Tools get built for jobs, and then they wander. What job was this one built for? Is it doing that job? And who gets to speak (or write, or spell) while it does?

The label of “profound autism” talks *about* people. It doesn't talk *with* them. In this essay you'll hear from some of the people it claims to describe, in their own words, because that's who we should really be listening to.

Where “Profound Autism” Came From

The term arrived in December 2021 in a report from the Lancet Commission on the future of care and clinical research in autism, signed by 32 representatives from ten countries, according to historian Marga Vicedo's 2023 account in *Frontiers in Psychology*. The Commission proposed it as an “administrative term,” meant to draw attention to Autistic people whose needs require lifelong, round-the-clock care, as the authors of a 2026 consensus study in *Molecular Autism* describe it. It isn't an official diagnosis. Amy S. F. Lutz notes in *Psychology Today* that it would first have to be adopted by the DSM or the ICD.

Lutz also quotes the Commission's definition. It covers Autistic people who need 24-hour access to an adult caregiver, can't be left alone in a residence, and can't manage basic daily needs. In most cases, the Commission said, that comes with a substantial intellectual disability (an IQ below 50), very limited language, or both. The Commission cautioned that the term isn't appropriate for young children and might begin to be useful around age eight, with families' consent and participation.

In 2023, CDC researchers led by Michelle Hughes applied a version of the idea to surveillance data in *Public Health Reports*. They counted 8-year-olds as having profound autism if they were nonverbal, minimally verbal, or had an IQ below 50, a surveillance-data proxy for the Commission's idea rather than the full definition. Across 20,135 children at 15 sites from 2000 to 2016, 26.7 percent met that proxy. In 2016 the rate was 4.6 per 1,000 8-year-olds.

Researchers kept using different versions, Lutz explains: some included children younger than eight, some used an IQ cutoff of 70, some added self-injury or aggression. So the Autism Science Foundation and the Profound Autism Alliance funded a modified Delphi process, and its research definition debuted at the International Society for Autism Research meeting in Seattle in spring 2025. According to the published study by Matthew Siegel and colleagues, more than 70 researchers, clinicians, caregivers, and Autistic people took part, and 76 percent of respondents agreed on the final wording. Lutz lists its parts: an autism diagnosis; an age of at least eight; supervision beyond what's typical for the person's age; adaptive skills far below age level, with an inability to independently do most daily living activities; and either an IQ under 50 or generally no

speech beyond single words or fixed phrases, all persisting across settings. The Profound Autism Alliance stresses that the definition is “a research tool, not a label for individuals.”

The term has since moved from journals into policy. On August 27, 2026, the Interagency Autism Coordinating Committee adopted its 2026–2028 strategic plan, which, Disability Scoop reported, includes a focus on “profound autism” for the first time.

The Problem it Claims to Solve

Start with the research. A 2019 review in the *Journal of Autism and Developmental Disorders*, led by Amy Stedman, examined 367 treatment studies of children with autism published between 1991 and 2013. According to the review, the share of studies that included “severely affected children” fell significantly over time, and studies measured and reported severity in wildly different ways. Lutz, a historian of medicine and vice president of the National Council on Severe Autism, points to that exclusion when she argues for the term. You can't plan services for people you can't count, and you can't count people nobody has defined.

Then there are the planners and the families. Vicedo, in that same 2023 essay, calls the Commission's proposal a pragmatic answer to the old problem of one diagnosis covering very different needs, and she credits it with drawing attention to Autistic people with “deep cognitive disabilities”, who have historically received less notice and less support.

Judith Ursitti, president of the Profound Autism Alliance, told Disability Scoop in July that caregivers of people with profound autism often “can't even get a shower for themselves every four days.” In other words, caregivers are exhausted and feel like they are being treated as background noise to other people’s arguments.

I am not without compassion on this: When someone needs help with basic daily care and they aren’t getting sufficient services and supports, it’s clear that the system is broken. I worked for years as a Direct Support Professional (DSP) and saw this dynamic in real time. DSPs are on the front line of support for overwhelmed parents and caregivers, but the system doesn’t allocate anywhere near the funds required to hire DSPs to give parents respite and give people with autism the attention and care they deserve.

The question is whether this “profound” label repairs the broken system.

Why Labels for “The Severe End” Keep Failing Us

We've been here before, under different wording. A term starts out as shorthand for planning services, then hardens into identity, then stigma, then a gate.

Start a century back: *idiot*, *imbecile*, *moron*, *feeble-minded*. The Senate committee that took up Rosa's Law, the 2010 federal law that replaced "mental retardation" with "intellectual disability" in federal health, education, and labor statutes, noted that all of these older terms were used for people with cognitive disabilities, by the public and in federal statutes alike, and that the terms for this group had gone through a steady evolution over two centuries, each one describing people in a pejorative way.

When Congress finally struck “mental retardation” from federal law, the committee called it “anachronistic, needlessly insensitive and stigmatizing, and clinically outdated.” Steven Kapp, an Autistic psychologist and Senior Lecturer at the University of Portsmouth in England, in a 2023 review in *Education Sciences*, points out that children assigned the older labels were also graded on their supposed educability.

The word “profound” has its own résumé. In the DSM-IV, according to the Johns Hopkins Psychiatry Guide, profound was the most severe rung of the mental retardation ladder (mild, moderate, severe, profound), reserved for an IQ below roughly 20 to 25.

Autism's own founders resisted the sorting. Kapp notes that Leo Kanner's 1943 paper credited the children he studied with good cognitive potential even though most had been treated as “feebleminded”, and that Kanner objected both to IQ tests and to the institutionalization of a girl he believed had been underestimated.

When Lorna Wing proposed a spectrum in 1981, Kapp writes, she didn't mean a line from mild to severe. She saw autism as multidimensional. Yet “high-functioning” and “low-functioning” rushed in to fill the space. They were never official diagnoses, and Kapp's review finds they lack validity. A 2020 study led by Gail Alvares found that intelligence is an imprecise predictor of functional abilities at diagnosis. Amy Sequenzia, a nonspeaking Autistic activist, has described who built those labels: non-disabled people who saw Autistics as lesser and needed to grade us so they could apply their assumptions and try to fix us.

Then came the tidy-up. Vicedo reports that the DSM-5 folded the old subtypes into a single diagnosis in 2013. Kapp explains that the DSM-5 workgroup opposed a severity scale, but the American Psychiatric Association imposed one anyway, reframed as levels of support need. The DSM-5's own text advises against using those levels to decide who is eligible for services. Australia's National Disability Insurance Scheme uses them for eligibility regardless. Planning shorthand, promoted to a gate.

That's the pattern, and Vicedo states its stakes plainly: psychiatric categories have often been used to establish hierarchies of social value, and children with cognitive disabilities, including Autistic children, were often warehoused in inhumane institutions. (Anyone familiar with the landscape will recognize that the inhumane warehousing continues today, most prominently at JRC, but not only there.) The Autistic Self Advocacy Network (ASAN) recognized “profound

autism” as belonging to that lineage from the start. In December 2021 ASAN called the term an attempt to rebrand functioning labels.

What the Label Risks in Practice

Here's how a label does its work. Sequenzia, in a 2013 post on *Ollibean*, describes what happens when doctors and other “experts” call a child “severe”: families adopt the word, and expectations for that child stay low. Her answer is short and hard to argue with: “Those are YOUR labels, they are not part of who we are.”

Ido Kedar, the boy with the flashcards, addressed stigmatizing labels. In his 2014 essay he writes that his instructors took his mistakes as proof he lacked comprehension. When he was around six, his mother Tracy Kedar recalls in a 2013 guest post, a doctor told the family it would soon become clear whether he'd spend his life as a “low functioning” autistic person. He had no way yet to tell anyone what he knew.

These harms aren't abstract:

Guardianship and institutions. The Autistic Self Advocacy Network's new toolkit warns that a “profound” label could make it easier to put people in institutions and to push families toward guardianship. Kapp adds that the term's rhetoric might inadvertently encourage parents to seek conservatorship instead of supporting their children to make their own decisions.

Schools. Kapp reviews a study of segregated classrooms for minimally speaking autistic children in which adults missed many of the children's attempts to communicate and only one of 36 students used an AAC device.

Treatment defended by severity. The Judge Rotenberg Center in Massachusetts is the only facility in the country that uses electric skin shocks on people who self-injure or act aggressively. According to WBUR, Boston's NPR news station, its defenders call the shocks a “life-saving last resort.” A federal appeals court vacated the FDA's 2020 ban in 2021, ruling the agency lacked authority to ban a device for one particular use.
I worry that the more a label says someone is beyond ordinary approaches, the easier it gets to defend what would never be tolerated for anyone else.

Research and policy. Kapp observes that the Commission's concept treats inability to self-advocate as typical of the group, though few Autistic people contributed to the report. The ASAN

toolkit warns that researchers who assume no one with the label can speak for themselves will stop asking.

The movement. In February 2022, more than twenty organizations of Autistic people called the label “highly problematic” in an open letter to the Commission, as Vicedo reports. Kapp describes what dividing labels do to advocates: when an Autistic person speaks for others, they're dismissed as either too autistic to have insight or not autistic enough to represent anyone. The toolkit adds that separating out people with the highest support needs hurts the people separated, the people who love them, and the movement itself.

None of this requires assuming bad faith. Many parents and clinicians want services and want to be seen, and the toolkit itself acknowledges that some Autistic people have started describing themselves as profoundly autistic. My concern isn't anyone's intent. It's what the machinery does once it's running.

What’s Real Underneath the Label

Here's what I don't want lost: Support needs are real. Some Autistic people need help around the clock, and saying so doesn't require branding them a separate kind of person. The difference is between describing what someone needs and declaring what someone is.

Danny Whitty is a nonspeaking Autistic writer and advocate. With his sister Tara, his communication regulation partner, he co-hosts a podcast about interdependence. In an episode on the words used for people like him, he explains his need with the precision of someone who has thought about it for years: “I cannot use speech as a reliable form of communication.” Notice what that sentence does. It names a specific need and it comes with a specific solution: in the same episode he says he's very verbal when his disability is properly supported. And his words need no diagnostic category to work. He also names the cost of the wrong word: he says “nonverbal” is part of a bias against giving people like him real education and opportunity.

Ido Kedar does the same thing from another angle. In his 2014 essay he lists his own needs plainly: limited independence in self-care, flat affect, no way to express his ideas by speaking, poor fine and gross motor control, impaired initiation, and trouble controlling intense emotions. Then he lists his life: a full-time student in honors classes, a cook and hiker who studies piano and helps care for a horse, someone with friends. That list would serve a service planner better than any adjective.

Support can be described at the scale of a whole life, too. Kapp tells of Joaquin, a minimally speaking Autistic man regarded as having significant intellectual disability, with a history of aggression, self-injury, and seizures. He lives in his own house with around-the-clock paid support staff, neighbors who accept him, and chores and walks he enjoys. His sister, who understands his speech, helped him leave an institution. He needs 24/7 support and he has a home of his own where he lives with dignity and autonomy. Both are true and a label like “profound autism” risks limiting him to being viewed only as someone with high support needs.

Needs can shift and move, too. Kapp reports that in the Commission's own dataset, some people retroactively labeled as profoundly autistic left the category as their language and ability to produce IQ scores improved, and that the category's stability was 83 percent, compared with about 91 percent for autism as a whole.

What to Do Instead

Describe needs specifically, one person at a time. The Delphi definition is already made of needs: supervision because of risks like elopement, injury, or lack of awareness of the environment; help with bathing, food preparation, and dressing, as Lutz lists them. Keep the parts, drop the label. A plan that says exactly what support someone needs, when, and from whom does more work than any adjective. The Autistic Self Advocacy Network made the same point in 2021: the label doesn't tell anyone *why* a person needs support or what support they need.

Fund services on assessed need, not on a label. Kapp notes that the DSM-5 advises against tying its support levels to eligibility, and he recommends that families, with good support, consider supported decision-making instead of guardianship.

Include Autistic people with high support needs in research as participants, not only as subjects. According to Kapp, the Lancet Commission itself says that meeting Autistic people's needs requires our inclusion and participation. Even the Delphi steering committee sees an opening: Siegel told Lutz the process exposed a need for better tools to measure IQ and adaptive functioning in the people with the most challenges. Kapp reviews a study of 30 minimally-speaking Autistic children in schools for “profoundly impaired autistic children”. They couldn't complete a standard verbal IQ test, but almost all completed a nonverbal one and averaged an IQ of 83. He also notes that interviews can be designed to include minimally speaking youth, including one with an IQ of 33.

Presume competence. Elsa Jean Pace, a nonspeaking Autistic self-advocate with apraxia, calls “presume competence” the motto of the apraxia community. She credits a therapist who works on the body–brain connection, plus a letter board, as “the way I became a person that people see.” That’s not a metaphor. It's a description of access.

Guarantee communication access. Kapp's review found that speech-generating tablets increased speech and communication for minimally speaking autistic people, and that the effect lasted. Yet in the segregated-classroom study, one student in 36 used AAC. Communication access isn't an add-on. It's the front door: to assessment, to school, to consent, and to self-advocacy.

In Closing, I Call for Solidarity

The old adage says we're more alike than different. We need to support the Autistic people the world finds hardest to hear. We need to refuse an unfair trade, even when it's being called "progress". A movement that can be divided into "profound" and everybody else is a movement that can be conquered. It's a movement that drains its own power by allowing a significant number of us to be spirited away into a linguistic silo that will surely translate into a real physical and social silo.

Solidarity doesn't mean we're all identical. It means refusing to let anyone's needs become the reason we stop listening to them. The people this term is meant to help can already tell us what they need. Some of them are typing it right now. Others will be able to tell us if we keep supporting them and helping them find their voice, be it through Spelling, sign, or whatever works for them and gets them heard.

We can keep allowing people to talk about them, or we can start talking with them. I already know which conversation I want to be part of.

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Review: NeuroLyrical Cafe: A Space for Spellers' Voices

I went to NeuroLyrical Cafe tonight and had a blast. It's a supportive space for spellers to share poems, music, artwork, and anything else creative. You don't need to be an experienced presenter, and first-time shares are celebrated.

There's also a collaborative writing prompt where everyone who wants to (presenters and audience) contributes a line to a group poem. It's an affirming community, a wonderful place to enjoy art and poetry, and a great opportunity for spellers to let people see their voice and creativity.

NeuroLyrical Cafe meets on the last Friday of every month. The next one is October 30, with a Bad Omens/Halloween theme, and costumes are encouraged.

More information: https://i-asc.org/events/neurolyrical-cafe/

Maxfield Sparrow, AutCom Board Member
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Maxfield Sparrow



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). For Sparrow's books, blogging, and more, visit https://maxfieldsparrow.com

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AutCom Film Sponsorship Announcement:

AutCom is excited to announce that it is an official sponsor of Jennifer Msumba's feature length documentary film, "The Fish Don't Care When It Rains." We encourage you to watch this important documentary when it becomes available and to join Jennifer Msumba, AutCom, and other organizations and individuals in the fight against the painful electric skin shock used at the Judge Rotenberg Center in Massachusetts.

“What I need is ninjas, to go in and save everyone. But I don't have ninjas, so I'm making this documentary instead." – Jennifer Msumba

Jennifer Msumba, a presenter at the AutCom Conference in 2019, experienced seven years of painful electric skin shock at the Judge Rotenberg Center (JRC) in Massachusetts. She made this documentary to share the story of what she endured there, and also the work she has done to recover from the trauma of those years.

“It’s like because we are disabled, somehow we aren’t considered the same human as everyone else. But we are.” – Jennifer Msumba

To view the trailer and to sign up for updates on the film: https://the-fish-dont-care-when-it-rains.base44.app

See Max Sparrow's review of the film below.

Review: The Fish Don't Care When It Rains

By Maxfield Sparrow

Content note: this review describes electric shock, restraint, and food deprivation.
The Fish Don't Care When It Rains is a stunning, beautiful, horrifying, important film. https://fishdontcaremovie.com It is streaming through October 18 ($15 + $1.50 processing fee): https://watch.eventive.org/heartlandfilmfestival/play/6a8caa0d26f98166f0238d0e

The film follows Jennifer Msumba, an Autistic musician who survived the Judge Rotenberg Center (JRC), the Massachusetts institution that uses electric shock as "treatment." Msumba, who goes by Jen, also co-directed the film with Siobhan McDonnell, so the story comes to us in her own voice.

The title comes from one of her songs, and its central image is a precise picture of living with what has already happened to you:

“Oh, the fish don’t care when it rains, they’re already wet … And I can’t change where I’ve been, I’m already hurt.”

Rain cannot make the fish any wetter, and Msumba cannot change where she has been.

Msumba grew up in Boston and developed severe OCD from an early age. She was hospitalized at seven, sent away at fifteen, and eventually landed at JRC, where she spent years counting

popsicle sticks for eight hours a day. "And we got paid a penny a bundle," she says. "And when I say we got paid, we were supposedly paid because I never saw any money, ever."

Forced labor was only one part of it. According to the film, Msumba had an electrode backpack locked onto her body 24 hours a day. The device, the GED, delivered shocks nine times more powerful than a cattle prod, meant to "train" her to behave "properly."

As she recounts it, she was shocked for getting out of bed without permission, saying no, screaming in pain. She was also shocked for crying while shackled to a board, stripped naked, and scrubbed, which she describes as equivalent to repeated sexual assault. "And I would just cry and cry and cry and cry and cry," she says. "And tears would just come and coming, coming because I just wanted them to stop."

Her program's rules were impossible to meet. She wasn't allowed to speak on her own, yet had to answer staff within five seconds, with no repetition, no "bizarre speech," and no "inappropriate tone." Her meals came in bite-sized cups earned every thirty minutes, and any minor infraction meant a cup was thrown away. She threw away entire meals. She was starved whether she tried to comply or not.

The film reports that JRC costs $300,000 to $500,000 per student per year, paid with public money, not by parents or insurance. Massachusetts and New York taxpayers have paid over $170 million in ten years, while top administrators earn up to $450,000 a year. The film also notes that the United Nations classifies the shocks as torture.

The film ends with a "Rest in Peace" card naming six people who died at JRC or its predecessor, the Behavior Research Institute: Danny Aswad (14), Robert Cooper (25), Linda Cornielson (19), Abigail Gibson (29), Silverio Gonzalez (16), and Vincent Milletich (22). A Massachusetts court found the center negligent in Cornielson's death in 1995, and a court also cited the founder for negligence in Milletich's.

Efforts to stop the shocks have repeatedly stalled. A federal appeals court vacated the FDA's 2020 ban on the devices in July 2021, ruling on the agency's authority rather than the evidence. The FDA proposed a new ban in March 2024, and in July 2026 it announced a new target of November 2026 after missing two earlier deadlines. JRC remains open.

Msumba got out. She won her own guardianship hearing and moved to a facility in Florida, which she calls the opposite of JRC in many ways. She built a life around music. "When I'm playing music, like, all my tics and, like, obsessions and stuff, they just melt away," she says. "And I'm just doing music. It's magical."

She plays guitar, piano, and many other instruments, and her songs are heartfelt singer-songwriter music. Most are upbeat, even when sad or frightening events inspired them. The

music does not look away from what happened. it carries truth and sorrow but with a deep strength and faith that leans harder on hope than darkness. Her songs are featured throughout the film, and they are SO GOOD.

Msumba's story is angering and sad, but I cheered when she got out of JRC. Many others did not, and people are still being shocked there today. Watch this film and share it with the people in your life.

#StopTheShock protesters in the film say what many viewers will feel: "We have to shut this place down." And, "We should not send them any more dollars that they use to coerce our legislators, our cowardly legislators."

Here are three ways to help while decisions are still pending:

- Back the federal ban. The Autistic Self Advocacy Network keeps tools for contacting officials on its #StopTheShock page: https://autisticadvocacy.org/stoptheshock/
- If you live in Massachusetts, ask your state legislators to end aversive "therapy." Bill H.245, which would have prohibited using physical pain to change the behavior of people with disabilities, was heard in November 2025 and sent to study in February 2026. Earlier bills have also died in committee. You can find your legislators at https://malegislature.gov/Search/FindMyLegislator, and the Alliance Against Seclusion and Restraint's Stop the Shock campaign is a good place to follow what comes next: https://endseclusion.org/2025/09/24/call-to-action-stop-the-shock-it-is-time-to-ban-shock-devices-and-aversive-therapies/
- Support the groups doing this work. The Autistic Self Advocacy Network and the Alliance Against Seclusion and Restraint both lead current campaigns.

The Fish Don't Care When It Rains (74 min), directed by Jennifer Msumba and Siobhan McDonnell, screened at the 35th Heartland Film Festival, where Msumba received the 2024 Carolan Iverson Award.

Additional sources (the film is the primary source for this review):

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New and Exciting

Events, Webinars, Conferences, Podcasts

Summit presentation recordings: Black Autism Acceptance Day Virtual Summit (YouTube channel): Full suite of presentations is available at the link. https://www.youtube.com/@blackautismacceptanceday

Online Mini-Summits: Autism Mustang Alliance (AMA): "Announcing our first virtual mini-summit!! For nonspeaking autistic advocates locally, around the country and worldwide, join AMA's Director of Advocacy and Community-Building Niko Boskovic as he gears up to launch his advocacy initiatives for the speller/typer community. The first of our quarterly Zoom mini-summits will be held on Sunday December 6 at 3pm Pacific/Los Angeles time. There is no fee and nonspeakers at all levels of communication are welcome to join!"

> Information on this event and how to participate are here: https://autismmustangalliance.org/online-mini-summits/
>
> More details on this and their future events on are also their website (see the menu there): www.Autismmustangalliance.org

Podcast: We Want To Tell You. Airs on The Beatles Channel.
"A monthly show hosted by Aiden Levy and Elizabeth Bonker, two Nonspeakers with Autism, who love The Beatles! Using text-to-speech technology, they share their enthusiasm with their own unique voices, heard across the nation!"
https://www.siriusxm.com/player/show/entity/2d0abe17-fb71-def5-46be-aac5ced8a39a?utm_medium=shared

Journal Article

The Work Before the Work: Lessons From Co-Designing Assistive Technology With Nonspeaking Autistic People. By: Sofya Gektin, University of Virginia; Sajad Sarlaki, University of Calgary, Grant Blasko, University of Washington; Kristen Gillespie-Lynch, College of Staten Island & The Graduate Center of the City University of New York; Isaiah Tien Grewal, Stony Brook Medicine School of Social Welfare; Vikram Jaswal, University of Virginia; Sujit Kurup, Autism National Committee (AutCom); Chandra Lebenhagen, Including Autism; Graciela Lotharius, Georgia Perimeter College; Elizabeth MacNeil, University of Alberta; Kyle Stauber, Caroline Rose Tallungan, University of Virginia; Lisa Vallado, Washington Adventist University; Diwakar Krishnamurthy, University of Calgary. July 9th, 2026.
https://autismspectrumnews.org/the-work-before-the-work-lessons-from-co-designing-assistive-technology-with-nonspeaking-autistic-people/ (See our Resources section for a link to the entire

Autism Spectrum News Summer Issue 2026, "Giving Voice to Nonspeakers: Communication, Advocacy, and Inclusion Across Life"
https://autismspectrumnews.org/wp-content/uploads/2026/07/ASN-Summer2026.pdf

Books

ALL WE KNOW…IS IN THE AIR: Poems and Passages by a Non-Verbal Autist Writer by Danny Costello (Author)
https://www.amazon.co.uk/ALL-WE-KNOW-AIR-Non-Verbal/dp/B0GNZ36YHJ

Autism, Identity and Me: A Practical Workbook to Empower Adults by Rebecca Dufus and Lyric Rivera (Neurodivergent Rebel)
https://neurodivergentrebel.com/get-autism-identity-and-me-a-practical-workbook-to-empower-adults-order-now/

Barrettes in the Mud: A Story in Poems and Piece. Tiffany Hammond (author). This book "is a lyrical exploration of poems, stories, and letters from acclaimed advocate and writer Tiffany Hammond. With honesty, Hammond explores the intersections of autism, Blackness, motherhood, and identity. . . This memoir invites readers into the complexities of living as a Black Autistic woman and raising two sons on the spectrum. Hammond's writing is intentionally accessible, with open space and short, powerful lines that honor neurodivergent readers and anyone overwhelmed by dense text."
https://www.amazon.ca/Barrettes-Mud-Story-Poems-Pieces/dp/B0GTJN9RBD

How Do You Spell Belong? Tiffany Hammond (Author), Ken Daley (Illustrated by). This is "a new picture book centering an Autistic young boy and celebrating friendship and inclusivity."
https://bookshop.org/p/books/how-do-you-spell-belong-tiffany-hammond/4f19d6793d501115

New Advocacy Organization

Communicators for Communication Rights - C4CR. "We Started With One Family's Story. We're building a movement for communication rights. Advancing the belief that communication is a human right—for nonspeakers and for everyone who needs support to be heard." Includes an opportunity to sign onto the Communication Rights Pledge.
https://comm4commrights.org/

Films

Room to Move documentary. "Room to Move, a 2025 Tribeca Film Festival World Premiere, is a deeply personal and visually expressive documentary directed by Alexander Hammer. The film follows acclaimed choreographer, performer, and educator Jenn Freeman as she navigates a profoundly transformative chapter: receiving an Autism Spectrum Disorder diagnosis at age 33." More information and the trailer at the link. https://www.roomtomovefilm.com/

All of Us movie-documentary. "When Ruby Bridges Elementary opened in Washington State in 2020, its founding principal and staff made a radical choice: to educate every child in the same classroom, regardless of disability or support needs. Five years later, the school is seeing strong academic and social outcomes, without additional funding or staff. There was no magic fix – just a new model based on the belief that inclusion benefits everyone. All of Us is the story of a school that breaks the mold. A school that is unique, but shouldn't be. Learn how Ruby Bridges made inclusion work at allofus-themovie.com."
https://www.youtube.com/watch?v=1SQRK3Y-IaU

Ricochet by Dan Bergman

Serenade me with the sweet music of your coincidences
My universe, with all your moving parts,
Your people, buses, molecules, atoms.
Bless my quirks with your quarks,
And lend me your mischief so I can appreciate your intentions.

And not alone, dear universe but send me
A billiard ball to smack into me from her own trajectory.
But gently, so we sink into the same pocket together
Rather than ricocheting apart traveling to opposite sides,
But happily nesting in the same net,
No longer rolling, spinning, but still, against each other
While the game continues above us without us.

Or drop a horse next to me while I lie down in a forest clearing
And then drop a warm and loving woman next to the horse,
So that when we all roll to our feet we can ride off together through the forest,
Hooves thudding softly.
Do not make me weep after them as they ride off together without me.

Whatever happens, let the people I bump into
On my spinning journey be better off
As a result of me being struck with them.

Except for the woman who rides off without me.
Let her be knocked off the horse by an adventurous branch
Which fell in love with her and couldn't believe its luck,
When the thundering hooves approached.

And let me always appreciate what comes my way,
Not imagining that I ought to have had more
Money, or mental health, or seductive charm
Than you have chosen for me.

Your secret admirer,

Dan

October, 2026

Dan Bergmann is 31 years old. He has been living with minimally-speaking autism all his life. He learned to make language when he was 12 by pointing to letters on an alphabet board. Dan graduated from the Harvard Extension school in 2021, the first non-speaker to earn a Harvard degree. He "spoke" via text-to-speech computer at his commencement. He earned a postgraduate professional certificate in screenplay writing in 2026 from UCLA. He writes essays, poems, plays and screenplays. He is the author of, and leading actor in "Pointing Fingers" (2026), the first fiction feature-length film by and about people with non-speaking autism who communicate by typing.



ANNOUNCEMENT:

Annual Meeting of AutCom Members

The annual meeting of AutCom Members will be online December 13, 2026.

We plan to send an email to current members soon with a link to join the AutCom Annual Meeting of the Membership (via Zoom meeting). We will take the opportunity to review the year's activities, vote on a proposed slate of officers, and invite comments and questions from members. If you are an annual or life-time member, the AutCom Board hopes to see you and hear from you then!

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 Autism National Committee (AutCom)

As a member of 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
Join any time.
Renew each January
(except for Lifetime Members).

JOIN or RENEW online at www.autcom.org OR use the form below and send a check as indicated.

AutCom Membership Form – Annual or Lifetime

For the Membership Year _____ (January 1-December 31, except for lifetime membership)

Name _____**Date**:_____

Address _____

City _____ **State** _____ **Zip code** _____

Phone _____ **Email** _____

I want to ____ Renew my membership ____ Become a Member ____ Become a Lifetime Member

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

_____ Student _____ Professional (field) _____

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

____$30.00 (nonautistic person annual membership) ____$10.00 (student annual membership)

____$75.00 (supporting annual 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