

What can you do?

Teach all children about consent and boundaries. Respect their boundaries.

Pay attention to candidates in local, regional, and national elections. Who controls school curricula and interventions? Communicate with them your concerns and preferences.

If you are a parent of a disabled youth, you have the legal right to refuse any treatment a school system suggests, including ABA, restraint, and seclusion. You also have the right to request specific services.

Don't donate to organizations that support ABA, restraint, and seclusion. Instead, donate to organizations that seek non-violent solutions to conflict in schools, work against bullying, and/or organizations led by disabled people that advocate for disabled people.

If you meet a non speaking person in public, interact with them the way you would any other person of their age. Be patient, and let them tell you how to best communicate with them if you are uncertain.

Hire disabled people to work in every facet of society, and pay them wages equal to that of their non disabled colleagues.

Forge ways for disabled youth and disabled adults to connect through mentor-mentee opportunities (informal and formal).

Learn about disability cultures, disability rights, and disability access. Learn about systemic racism and classism. Learn about LGBT communities. Work to make your community more equitable.

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What is applied behavior analysis?

Applied behavior analysis, or ABA, is a field that applies behaviorist theory to interventions. Behaviorist theory suggests that cognition is a series of automatic responses to stimuli. Think of Pavlov's dog drooling when he hears a dinner bell. Outside of education, clinical psychology, and animal training (fields that often rely on compliance), behaviorist theory has largely been replaced with more modern theories of cognition.

ABA was popularized by Ivar Lovaas, a psychologist working at UCLA in the 20th century. He used aversives and rewards (called reinforcers by practitioners) to shape the behavior of autistic children to better match that of their non-disabled peers. He also worked closely with George Rekers to apply ABA to what we now call gay conversion therapy. The goal was to narrowly define what is normal, and arbitrarily change the behavior of anyone who doesn't fit that narrow definition.

The use of aversives has largely gone out of fashion, with the horrifying exception of the Judge Rotenberg Center, which still uses painful skin shocks. Modern ABA still seeks to change the outward behaviors of people who do not fit in without questioning whether those behaviors may be neutral or beneficial, and relies on restraint and seclusion to enforce compliance when students resist. Physical restraint and seclusion has led to the serious injury and death of many students, and is used more often with students of color, especially black students. It does nothing to help autistic and other disabled people develop skills for self determination and self care.

For more information:

Modern use of aversives in ABA: <https://adapt.org/jrc/>

The empirical (in)validity of ABA: <https://ies.ed.gov/ncee/wwc/Intervention/743>

<https://doi.org/10.1007/s40614-019-00191-5>

Regarding the generalizability of single case studies:

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3369519/>

Compliance and violence:

<https://sociallyanxiousadvocate.wordpress.com/2015/05/22/why-i-left-aba/>

www.thekidswelose.com

<https://theaspergian.com/2019/03/27/is-aba-really-dog-training-for-children-a-professional-dog-trainer-weighs-in/>

Kupferstein, Henny. (2018). Evidence of increased PTSD symptoms in autistics exposed to applied behavior analysis. *Advances in Autism*.

Gay Conversion Therapy & ABA:

<https://catalystjournal.org/index.php/catalyst/article/view/29579/23427>

What is autistic culture?

Autistic culture is the idea that autistic people come together and build systems of shared values and social practices. Autistic culture is not a singular culture, but rather a term that encompasses many cultures with a similar shared central value around pride in who one is as an autistic person. Autistic cultures develop online in forums and social media, and in person in school clubs and classrooms, at advocacy organizations, and endless other spaces. One of the defining features of these autistic spaces is the prideful engagement in behaviors that ABA attempts to extinguish, such as flapping, humming, and other stimming.

Like other oppressed communities, autistic people engage in a large amount of activism, both virtual and physical. One focus of this activism seeks to redirect research funding away from cures for autism and towards supports for autistic people to live full lives. Autistic culture doesn't want to erase autism. Instead, it celebrates what it means to be autistic—including the very real struggles that many autistic people face, and how to navigate life with those struggles.

Autistic culture supports the idea that autistic people hold authoritative knowledge over what it means to be autistic, and how best to support autistic people in realizing their goals. Recent empirical research suggests that autistic people easily understand each other where non autistic people might be confused or offended. Where ABA ignores (and sometimes denies) the existence of thought and feeling, psychologists, anthropologists, and other scientists are finding more and more evidence that things autistic people report about themselves and their culture are true.

For more information:

Autistic Self Advocacy Network <https://autisticadvocacy.org/>

Autistic Women and Nonbinary Network <https://awnnetwork.org/>

Ollibeau <https://ollibeau.com/>

Loud Hands, edited by Julia Bascom, (Autistic Self Advocacy Network)

"The Deficit View and its Critics" by Dr. Janette Dinishak <http://dsg-sds.org/article/view/5236>

Stim, a short documentary by Marrok Sedgwick <https://youtu.be/2eCUtIFVixs>

<http://www.thinkingautismguide.com/>

<https://emmashopebook.com/tag/non-speaking-autistic/>

Research:

<https://pdfs.semanticscholar.org/5ab8/7e1853d4d9d2c25886507ea79216cbb54c06.pdf>

<http://dart.ed.ac.uk/wp-content/uploads/2019/04/Diversity-in-Social-Intelligence-Participant-Summary-.pdf>

The windows to our souls.

Marrok Sedgwick, B.S., M.F.A.

A common goal in ABA is to teach autistic people to make eye contact with other people. Community members have told me eye contact is painful, provokes anxiety, and is too intimate, suggesting that forced eye contact is a gross violation of bodily autonomy and consent. Occasionally I do encounter autistic people who enjoy it when it comes from people they trust and love deeply. Either way, it is clear that our eyes are not adequate windows into our souls. Our poetry, on the other hand, is.

Autistic poetry describes my community's innermost desires and emotions. Multiply disabled, non speaking self advocate Amy Sequenzia told me that poetry is sometimes easier for her to describe her life than prose. Her poetry, and countless other non speaking and speaking autistic poets, is featured in everything from printed poetry anthologies to zines to online blogs. Common themes include defiance, pride, stimming, and perpetuation of community values.

Autistic poetry is a political act. As I have written elsewhere, autistic poetry is meant to create, reinforce, and challenge the values that make up Autistic culture; to prove that Autistic identities and culture are valid, non-pathological ways of being in the world (even where medical supports, such as occupational therapy, might greatly benefit us); and to show that Autistic people, especially non-speaking autistic people, are both sentient and sapient. Poetry offers non autistics a highly accurate means of understanding who we are, and what change we seek from the world.

To experience more autistic poetry:

Michael Scott Monje, Jr.: *The Us Book*, (Autonomous Press)

Tito Rajarshi Mukhopadhyay: <http://dsg-sds.org/article/view/1192/1256>

David James Savarese: "A Doorknob for the Eye," from www.unrestrictedinterest.com & *DEEJ* (film) <https://www.deejimovie.com/>

Amy Sequenzia: <http://nonspeakingautisticspeaking.blogspot.com/>

Anthologies featuring multiple authors:

The Spoon Knife Anthology (a new anthology is published each year), various editors (Autonomous Press)

Typed Words, Loud Voices, edited by Amy Sequenzia & Elizabeth J. Grace, (Autonomous Press)

Unlocking Potential, a chapbook from www.unrestrictedinterest.com

The Sun Is In Me
By Huan Vuong
Vietnamese-American non-speaking autistic person,
self-advocate and author

The Universe is expanding and
is full of light, dark matter,
and all of the elements.

I am the source of the beginning
and the end of it all.

The edges of my body
are at the boundary
of rifts and trenches.

I am a mystery to everyone around me
except those who understand that my body
and my mind are sometimes disconnected.
My mouth is an engine full of words I do not
think and full of things I wish I could say.

The way my finger moves across the letter board
is the revolution of my planet
and the acceleration of my universe.
It is the poetry in me that refuses
to be silenced and forgotten.

I am a human being made of the Sun
and other stars. I am worthy
of so many beautiful teachings
and experiences. I am enough.

ABA is racialized violence

“Stand up” and now I am pulled to standing. “Sit down,” get pushed to sitting. Stand up sit down stand up sit down stand up sit down. Do what they say or your body will be made to do it anyway. The more insistently you refuse, the more vehemently they will make you. They’re bigger, they’re stronger, and they don’t consider you a real person.

Lovaas considered himself to be handing parents and therapists a roadmap to building a person. You can dress it up in “play based” all you want, but every second is coercion. Can you imagine holding everything an adult loves hostage until they do what you want? We all know that’s violence. It’s on every domestic violence checklist. We aren’t people until you say so, so you can do as you will.

Every stand up sit down cuts a bit of our soul.

When you don’t think someone will learn or progress at all without your micromanaging every moment, every word, movement, thought, and expression, you are saying they’re not a person til you program them to be one.

When you’re deciding to build a person from scratch, your blueprint is going to be for the person who you consider the default. The programs are for drilling white upper middle class scripts, norms, behaviors, grammar, body language.

Stand up sit down stand up sit down stand up sit down look at me.

I fought stand up sit down passively, but eye contact? That’s not just violating me, that’s violating my ancestors. We don’t do eye contact. You demand eye contact.

If stand up sit down was violent--and it was, doing that to an adult would get you arrested--then look at me was an all out war. I knew we don’t do that. The therapists should have known we don’t do that, but they consider building a person to have a specific order and eye contact is like laying the cornerstone for them. They dislocated my shoulders and bruised my arms and my chin. I bit them, squeezed my eyes, screamed, punched, kicked. They wrestled me to the ground and pried my eyes open. All for eye contact.

My ancestors are probably proud of how hard I fought for that piece of them, but I lost the war even so. The therapists tried systemically to take every bit of Asianness out of me and force me into a white girl mold.

And this is violence. This is racialized violence.

And then there's verbal behavior. Do you think the scripts they teach are appropriate in a Black American context? They certainly aren't in an Asian American context. And now they're exporting milquetoast WASP pleasantries and non communication to Africa, to South Asia, to Central America.

It's racism. They're colonizing our minds. When the psychological violence won't do, they will go with physical. And they'll claim it is for our own good, but it isn't. It's to whitewash our very beings.

Kassiane Asasumasu

Radical Neurodivergence Speaking, We Are Like Your Child, and other projects

<http://timetolisten.blogspot.com/>

To learn more about racialized violence in schools:

The Pedagogy of Pathologization: Dis/abled Girls of Color in the School-prison Nexus by Subini Ancy Annamma

DisCrit: Disability Studies and Critical Race Theory in Education, edited by David J. Connor, Beth A. Ferri, and Subini A. Annamma

<https://rewire.news/article/2018/03/23/violence-schools-tragedy-systemic-part-life-black-students/>

To learn more about other violence against disabled people:

<http://autisticadvocacy.org/wp-content/uploads/2015/01/ASAN-Anti-Filicide-Toolkit-Complete.pdf>

http://autisticadvocacy.org/wp-content/uploads/2013/03/ASAN-Organ-Transplantation-Policy-Brief_3.18.13.pdf

https://www.iancommunity.org/cs/ian_research_reports/ian_research_report_bullying

<https://juststimming.wordpress.com/2013/01/24/confession-of-a-woman-in-a-refrigerator/>

Perry, David. "The Ruderman White Paper: On Media Coverage of the Murder of Disabled People by Their Caregivers." Ruderman Family Foundation, March 2017.

Non-ABA Ways of Addressing Behavior in Autistic Children

Laura K. Anderson, doctorate student, University of Northern Colorado

ABA works extremely hard to extinguish "undesirable" behaviors in autistic children. But Board Certified Behavior Analysts (BCBAs) simply see the undesirable behavior and then develop a system of rewards or punishments to alter the behavior. They never try to understand why the behavior exists, understand behavior in the context of the crisis or dysregulation cycle, or understand and prevent triggers that lead to crisis. Rather, the emphasis is placed solely on changing the child's behaviors, not the environment or context in which the child lives or attends school.

Better systems for supporting someone with "undesirable" behaviors exist.

One such model is Collaborative and Proactive Solutions, which emphasizes determining situations where behaviors occur and then collaborating with the person exhibiting these behaviors to determine why and develop a plan together to handle these situations. By understanding what is triggering behaviors, we can circumvent the entire crisis cycle and teach two valuable life skills: Problem-solving skills and collaboration with others.

Additionally, by understanding that crisis behaviors are the result of the sympathetic nervous system, we can understand that undesirable behaviors are not intentional behaviors. Undesirable or challenging behaviors occur as a result of dysregulation, especially when someone is faced with more stress than they are capable of handling. By creating relationships based on safety, trust, and compassion, and assuring students that their behaviors are reasonable given the situation, we can support students by co-regulating their emotions with them instead of forcing behavioral changes. This deeper understanding of behaviors, and supporting the underlying causes, will lead to lasting change, positive brain development, and positive relationships with other people.

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Colvin, G. T. (2014). *Managing the cycle of acting-out behavior in the classroom* (2nd ed.). Thousand Oaks, CA: Corwin

Delahooke, M. (2019). *Beyond behaviors: Using brain science and compassion to understand and solve children's behavioral challenges*. Eau Claire, WI: PESI Publishing & Media

Forbes, H. T. (2012). *Help for Billy: A beyond consequences approach to helping challenging children in the classroom*. Boulder, CO: Beyond Consequences Institute, LLC

Greene, R. (2019). *Collaborative and Proactive Solutions*. Retrieved from

<http://www.cpsconnection.com/>