



The Communicator

A publication of the Autism National Committee



Introduction

As we welcome the arrival of spring, we reflect on the events and changes of the past year and dedicate ourselves anew to the vital work for better lives and futures for everyone in the autism community. This issue of our newsletter holds some real gems, with a new book excerpt, a poem, a flyer, articles, resources, and more from the AutCom 2021 Conference presenters and other changemakers in the autism community. We hope that 2022 will be a time of renewal and connection within the autism community, with broad collaboration on common goals of successful lives for all, including essential supports and services, accommodations, and welcome in every community for all autistics and their families and allies. Together we can make real progress.

Join us on Facebook! “**Like**” and share all our perspectives far and wide.

<https://www.facebook.com/autcom>



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The Problem of Attributing Negative Intentionality to Autistic Behavior by Judy Endow

Problems arise when we attribute willfulness to behavior of an autistic and then regard it as fact. One problem is that because it is not willful on the part of the autistic, when the assumptions of “won’t” or “doesn’t want to” are erroneously made, it is a difficult (if not impossible) platform on which to start a positive relationship with another human being. Just like it is difficult for any human being to learn skills, feel comfortable and thrive when those around him think poorly of him, so is it for autistics.

Another problem arises when behaviors observed are stated in language ascribing intentional negative attribute or willfulness to the autistic such as “he won’t” or “she refuses to” in that it can undermine problem solving the kinds of supports that might be helpful.

Classroom Example

Here is an example based on the assumption of classroom staff that a student did not want to listen or join conversations of non-interest.

I was called to see 5-year-old Max who was throwing toys at his classmates. When the classmates reacted in a negative manner such as shouting, “Stop that, Max!” or crying, Max would laugh and throw another toy at this child. Even though Max was getting negative feedback from his peers, it seemed to encourage him rather than deter him as evidenced by the increasing frequency of his behavior of throwing toys at his classmates.



When I asked the team if Max had a way to initiate conversation or request a classmate to play with him I was quickly assured that Max did not like to engage with other children and was given several examples such as he wandered around during Circle Time, never joining in and when the students did stations where they engaged in a variety of play activities in small groups, Max was never interested in their conversations or activities. Instead he picked up items in the station and threw them at the other students.

This team was stuck in their ability to solve the problem. When the neuromajority team members observed Max’s behavior their own neurology informed them. If they themselves had been wandering around during Circle Time or throwing toys at their classmates it would mean that they did want to listen or join in conversations or that the play wasn’t interesting to them. The team members were unaware that their own neurology was the base from which they tried to solve the problem.

The lens our neurology uses to look through at a particular situation outside of us is just that – the lens of our own neurology, propelling us to ask what would this behavior mean were I engaged in it? Our brain tabulates this information and provides us a sense making explanation without us even consciously thinking in this way or even being aware of the process! Yet, it is important to know our brains automatically problem solve for us in this manner even though we are not aware of our brains doing so.

It is important to understand when we make neuromajority attributions to autistics we are generally wrong AND it can cause us to become stuck in our own problem solving concerning the situation. This team hadn't even considered the possible communicative intent of Max's behavior because they thought Max was not at all interested in communication with his classmates or with anyone.

When Max's behavior was reframed as misguided attempts to initiate conversation and join in play this same team of people became great problem solvers! A month later when I returned to the classroom I observed Max affixing the Velcro cloud to the weather square during Circle Time and then sitting on the masking tape X – his visual spot to sit at Circle Time.

Follow Up

Three months later I observed Max choosing a visual mini schedule from the available options, each option sequentially outlining a way to play at the kitchen station. The mini schedule showed him exactly what to do and in

what order at the station. First a pan with eggs on the stove, next a spatula removing the egg from the pan, then putting it on a plate, and last saying, "Here is an egg to eat," while placing the egg on the table. Another student sat down and pretended to eat the egg.

Conclusion

Max had received direct instruction on what to do at Circle Time and what to do at the kitchen station. It turned out he really was interested and did want to join in the conversations and activities in the classroom. He just did not have the skills to do so. Once the skills were taught and his neurology supported he was able to join in with his classmates in a more effective and satisfying way than to throw toys at them and laugh.

This story shows the errors we can make when ascribing negative intentionality and willfulness to behaviors of autistics.

Selection from *Autistically Thriving: Reading Comprehension, Conversational Engagement, and Living a Self-Determined Life Based on Autistic Neurology*

Note: The author is autistic, intentionally uses identity-first language (rather than person-first language), and invites the reader, if interested, to do further research on the preference of most autistic adults to refer to themselves using identity-first language.

See Judy Endow's website for her blog, publications, art, videos, and more. <http://www.judyendow.com/about/>

In Memoriam: Anne Bakeman

It is with heavy hearts that we pass along this sad news. AutCom and the autism community in Vermont and beyond have lost a strong advocate, champion, and friend in Anne Bakeman. Devoted mother, wife, and Nana, Anne succumbed to cancer after a hard-fought, five-year battle on May 14, 2022. Anne was a fierce and persistent advocate for people with disabilities, including her daughter Jen, and sympathetic to disadvantaged and oppressed people everywhere.



Anne Bakeman and her positive influence will be profoundly missed. Anne was an active member of the Board of the Autism National Committee for many years. Since 2008 she served as Treasurer. Anne chaired Vermont's Howard Center's "Bakeman Commission" in the early 80s, was a member of the Vermont's Developmental Disability Council, and until recently, the State Program Standing Committee for Developmental Services. Anne also served on the Burlington, Bethlehem, Arad Sister Cities program for the last several years.

As we learned of Anne's death online, multiple tributes were shared. Anne was variously described as "a quiet but strong advocate," "gentle and fiercely committed/determined all at once," "one of the kindest, most reliable people I've ever met," "kind smart, and generous," and "a treasure."

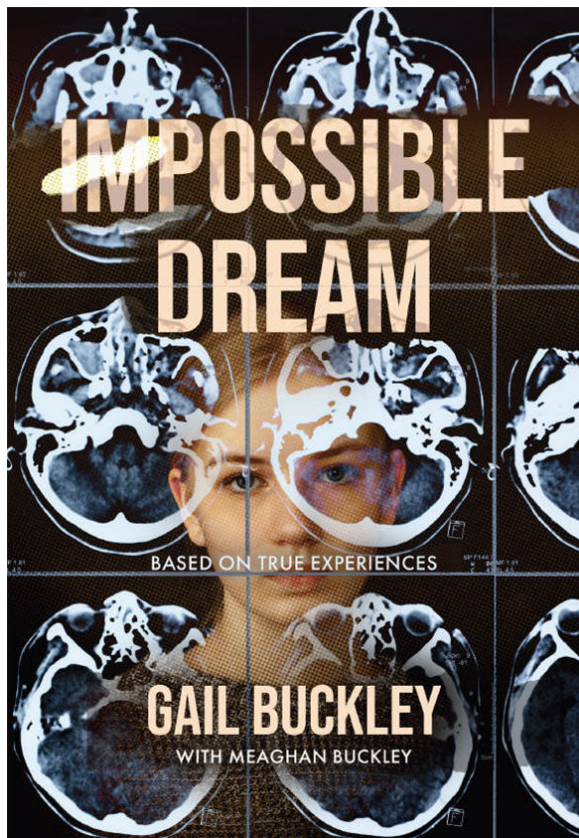
Anne's formal obituary began appropriately with a description of her interaction with her daughter Jen: "Come on in, JB" are the encouraging words Anne repeats as she ducks down to her shoulders in the cool Adirondack water of her cherished Blue Mountain Lake. Daughter Jenny, standing at the water's edge, replies quietly "No, no, no, no" following her usual hesitance inspired by her autism. But after fifteen minutes of repeated urging, Jen will have waded slowly into the water and then gently immersed herself with a smile and a sigh of contentment; she'll splash and paddle happily for another half hour at least."

We extend our condolences to Anne's husband Paul, their son Eric, their daughter Jen and all those who knew and loved Anne.

Meaghan's Introduction to imPOSSIBLE DREAM

(Meaghan's typed presentation at her ISP meeting in 2019)

I have listened enough. It is time for me to speak. I have a lot to teach the world about autism. I think that there is a lot of misunderstanding when it comes to how those of us with autism are perceived by the neurotypical world. If we don't do something, it is presumed that we can't do it, when in fact we might just not want to do it because it is too simple or elementary or because we are tired of it or bored with it. Our brains need to be continuously challenged or we will grow restless and frustrated and act out. Our behavior is our language. Unless we are allowed to type.



For me, typing is a natural means of expression, kind of like your voice is for you. I process language as written words. I always have. When I was first given the opportunity to type, I was so happy to finally have a way to communicate my thoughts. But then my voice was taken away from me and I was devastated, so devastated that I started pulling my hair out. I loved my long hair. I hated losing it. But I hated losing my voice more.



And I really felt sad that no one believed in me. It is important to me that you believe in me so I would like to set the record straight once and for all. I have autism. I am also very intelligent. These two things are completely compatible. My autism has no bearing on my intelligence. Autism makes it difficult to control my body, but my mind functions fine. The problem is the disconnect between my mind and body.

My mind tells my body one thing, my body does what it wants. So, in my mind I am able to formulate thoughtful language but what emerges from my mouth is often rote or repetitious.

When I type my body still wants to be in control. I have to focus hard to continuously fight the impulse to hit the same key over and over again. The funny part is, the part you doubt most about me, my facility with words, is the very least of my problems when it comes to typing. It is the visual motor part, not the mental part, that is the real challenge.

You see, my brain has no problem with words and grammar. If language processing topped at the thought level, I would get an A plus. The breakdown happens when it comes to combining words with sound, motor with sensory. The more intricate the neural processing task, the more ways my brain finds to screw it up. My mind just can't get coherent messages through to my mouth. Not just speech. I can tell myself to smile or stick my tongue out until I'm blue in the face but my mouth won't respond.

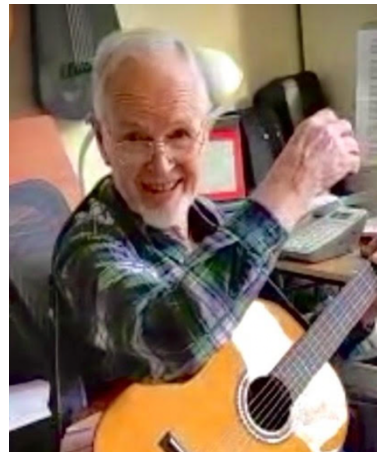
However, I can point my finger, and I can use my mind to direct where that finger goes. This may not seem like a big deal to you, but when I discovered that my finger could do the talking it was the very best day of my life. For almost thirty years all my words and thoughts were trapped inside my head and suddenly they were being set free. Typing opened up the pandoras box of my mind - and then it was slammed shut, without my having a say in the matter.

Those of us with disabilities need to have a say, and for many of us having that say requires an alternative means of communication. Requiring slight support does not mean that we are

stupid or incapable. It just means that it is much, much harder for us to do the simple things that you neurotypicals take for granted.

Those of us with autism are not crippled but rather blessed with having heightened sensitivities and abilities. That is, if you look beneath the surface. Having autism is a strength not a weakness. Not being able to communicate this to those who so misjudge us is the ultimate irony and tragedy.

In Memoriam – Doug McClennen



With sad hearts, we report the passing of Doug McClennen, whose association with AutCom has spanned

many years. For the past several years, Doug has performed the critical and challenging tasks of laying out and formatting the newsletter. On occasion, he also served as photographer and general helper with conferences. He was a clinical psychologist and husband to Sandi, who introduced him to AutCom. In addition, Doug was an accomplished sailor and singer of songs, his specialty being folk songs and sea shanties. We will miss his good humor, kindness, and dedication to AutCom and our mission.

2022 Comes in Like a Lion... Observations from the AutCom President

Hello everyone! I hope that you are finding yourselves in good health. The past two years have been trying ones for Americans, in many ways. During the worst of it, many of you, either autistic or supporting those who are autistic, have struggled with school and day support service and program closures. Trying to navigate all the mandates and the CDC guidance issuances has been challenging for those of us who don't suffer from anxiety; I can't imagine what it has been like for those who do!

In the midst of all the turbulence, some good has come about, at least for some. As we have heard from many autistics for years, autism involves neurological and sensorimotor systems. In recent months, more and more research has emerged indeed recognizing autism as based in neurological and sensorimotor systems and not behavioral and intellectual impairment. Several books have been published by autistics, offering their point of view in how they see the world. A few noteworthy films have been produced, including *The Reason I Jump*, and *This is Not About Me*. If you have not watched them, please do so now.

One of our Board members, Meaghan Buckley, and her mother have collaborated on a book that was being published in February, called *Impossible Dream*. As Meaghan discusses in her book, medications that were presented to her as anti-depressant and cognitive-boosting have not been as effective as promised. She has recently been recovering from their side effects, after taking them for more than 20 years. While taking them, she became catatonic and stopped eating and drinking before her doctors recognized (at her mother's insistence) that the medications were at fault. Her slow recovery is underway. You can read an excerpt from *Impossible Dream* in this newsletter.

Last year's AutCom 2021 Conference was a huge success. The first day of the conference addressed autism and employment, while the second day focused on autism and interactions with law enforcement and first responders. The morning keynote presentations were followed by afternoon panels of autistics, both individuals who speak and those who use other ways to communicate, including typing or spelling. We were thrilled with the presentations, attendance, and participation in this our first online venture. Elsewhere in this newsletter, we have included resources provided by presenters on employment as well as safety and law enforcement issues. Watch for more articles by conference presenters in future editions of this newsletter.

At this point, I would like to add my personal views in reflecting on 2021 and continuing concerns. As a Speech-Language Pathologist (SLP), I have spent the better part of the last two decades locking horns with my own professional organization, ASHA. This august organization has taken steps that have resulted in disenfranchising autistics in the following ways:

- ASHA aligns itself with financially well-endowed groups like Autism Speaks and ABA; in fact,
- ASHA is in the process of requiring SLPs to become ABA-certified, while ignoring the fact that “evidence using the scientific ‘gold standard’ for validating ABA outcomes (randomized controlled trials, or RCTs) is scant.”
- ASHA has also proclaimed that Rapid Prompting Method (RPM) and Facilitated Communication (FC) are prohibited methodologies, despite the overwhelming evidence of their success for many individuals.

Regrettably, autistics are routinely given standardized tests, despite the fact that they cannot respond in standardized ways. The results of these inappropriate tests follow the individual throughout their academic and vocational careers, and limit their opportunities and potential. As Dr. Clarissa Kripke (pediatrician) has said, however, “Speech is a motor function and language is a cognitive function and you cannot assume anything about the intelligence or cognitive functioning or language of someone who cannot use speech to communicate.”

The SLP student is taught that verbal speech is the gold standard of communication, and Augmentative and Alternative Communication (AAC) is discouraged until all efforts at producing speech are exhausted, usually around first grade. Even then, as Dr. Kripke has noted, the risk of abuse can be far greater with PECS and the electronic PECS-like AAC apps, because an adult has total control over the universe of what the individual is allowed to communicate.

Moving forward, it is more important than ever to listen to and learn from autistics, shift attention to the critical need for communication access for all using methods they find effective for themselves, educate all in the new paradigm for understanding autism, and work to build inclusive schools, businesses, and communities that are welcoming and supportive for all.

I will leave you with these words from Meaghan Buckley:

I get upset with everything being blamed on autism. It seems to be a catch all for problems of every type. I want you to know that my autism is not the problem you think it is. Keep an open mind when it comes to treating us unless you want to limit us even further. We will often surprise you if you trust in our ability rather than focusing on our disability. You tell others just your version of what you see in us, but we are the ones who are experiencing it from the inside and you have no idea what that is like. It is so frustrating to always be viewed through the lens of our behaviors. Try thinking about what is causing them. Yes, sometimes it is our autism, but more often it is the limitations just living with the diagnosis places on us.

We hope that your 2022 is taking shape to be a good one!

Lisa Keller

Tracy Thresher's Answers For the 10/15/21 Autcom Employment Panel

1. What obstacles have you faced over the years in obtaining meaningful and rewarding employment?

The biggest obstacle has been not being able to talk and needing support to communicate my thoughts. Without support I can't connect with people in a meaningful or intelligent manner. With typing I can get in the mix and people can get to know the real Tracy. Another big obstacle with not being able to talk, people think I don't have intelligence and don't have anything to offer, leaving me out of employment opportunities.

2. What kind of work supports have you received that helped you on a job?

The most important support has been a skilled communication partner which enables me to communicate my thoughts and ideas. With the ability to express myself through typing I have been able to fulfill my purpose in life to educate others about presuming competence. I have been to do the things I dreamt of doing and that has improved my quality of life.

3. How has the interview process gone when you have applied for jobs? Are there things that could be done to improve it such as focusing on the skills required rather than the social-emotional aspects of the job?

The interview process has more often been difficult because people don't take the time to listen and ask questions and talk way too fast. It's important that I have the interview questions ahead of time so I can type out my thoughts. That helps with not feeling under pressure to hurry up and I can still add my thoughts during the interview.

4. How do you think your experiences as an autistic person compare to those of other groups who have found it difficult to find good jobs? (e.g. people from racial or ethnic groups that have experienced discrimination, LGBTQ individuals, people with physical impairments, etc.)

I think that people make unjust judgements about people that are different and don't take the time to get to know us. It is unfair and puts us on the outside of society limiting our employment opportunities.

5. Despite all the struggles and tragedies of the pandemic, has anything good come out of it with respect to autistic people and work?

As bad as the pandemic has been there has been some good things like getting rid of Trump and having Joe Biden in office. I also am grateful for zoom and being able to do my work virtually like this panel. The other



positive is my mom and I have spent more time together and we have been able to communicate more often through typing.

New and Exciting

Documentary and Toolkit:

This Is Not About Me: A story about growing up nonspeaking. Film by Marco Niemeijer. This documentary focuses on Jordyn Zimmerman, a nonspeaking autistic woman who learned to communicate by typing as a teenager, and fought to follow her dream of becoming a teacher.

<https://thisisnotaboutme.film/>

A Toolkit for Educators of Students Who Cannot Rely on Speech to be Understood
Primarily authored by nonspeaking autistic AAC users Cole Sorensen (B.S., Special Education) and Jordyn Zimmerman (M.Ed. pending) for CommunicationFirst

<https://thisisnotaboutme.film/wp-content/uploads/2021/10/CommunicationFirst-This-Is-Not-About-Me-Toolkit.pdf>

Books

The #ActuallyAutistic Guide to Advocacy: Step-by-Step Advice on How to Ally and Speak Up with Autistic People and the Autism Community by Jenna Gensic, Ph.D., and Jennifer Brunton. Jessica Kingsley Press, 2022. "...an in-depth look at the key elements of effective, respectful, inclusive advocacy and allyship. Every topic was chosen, shaped, and informed by over 100 #ActuallyAutistic perspectives."

<https://www.amazon.com/actuallyautistic-Guide-Advocacy-Step-step/dp/1787759733/>

The Autism Industrial Complex: How Branding, Marketing, and Capital Investment Turned Autism into Big Business by Alicia A. Broderick, Ph.D.. Myers Education Press, January 2022.

<https://myersedpress.presswarehouse.com/browse/book/9781975501853/The-Autism-Industrial-Complex>

The Autism and Neurodiversity Self Advocacy Handbook: Developing the Skills to Determine Your Own Future. By Yenn Purkis and Barb Cook. February. 2022.

<https://us.jkp.com/products/the-autism-and-neurodiversity-self-advocacy-handbook>

Hostage to Silence by Brady Wright, autistic poet. Artwork by Gentry Goshell. "For years in silence, I have watched the world from a dormant life of observation. I hear through the sounds of chatter and pick out word by word. I hear sounds of nature like orchestras of harmonious creatures seeing their story. My writing is me opening you up to my corner of the world and singing a story of loss, hope, freedom and triumph."

<https://www.hostagetosilence.com/post/hostage-to-silence-the-book-is-now-live>

Life After Lockdown: Resetting Perceptions of Autism. Collaboration by over 40 authors, including autistic professionals and individuals on Becoming Social Again, Back to School, Adults in Transition, Into the Community, Reboot. AAPC Publishing, September 22, 2021

<https://www.amazon.com/Life-After-Lockdown-Resetting-Perceptions/dp/-1956110038aa>

Education

Communication for Education: A training program for staff who support students using text-based multimodal communication in educational settings. Collaboration among California Lutheran University's Autism and Communication Center, Reach Every Voice, and Autistically Inclined.

<https://www.communicationforeducation.com/>

High School Health Curriculum, designed for AAC users and accessible to everyone. This curriculum is designed to be used by people who are at least fourteen (14) years old, and/or those who are ready to learn about high school-level health topics. It can be used as a comprehensive curriculum and/or a supplement to an existing program. Some design elements are created to be #accessible by people who point, spell, and/or type to communicate (#AAC users), and all materials are appropriate for people with and without #disabilities. Author: Molly K. Rearick Day, EdD; Editor: Susie Lotharius, Med; Designer: Kristi G. Day (2022)

www.mollykrearick.com/shop

Podcasts

Interview with Sydney Edmond, autistic artist and poet, on Doug Blecher's 'AUTISM STORIES' podcast (Autism Stories Episode #158).

<https://anchor.fm/autism-personal-coach/episodes/Autism-Stories-Sydney-Edmond-e1c4nbr>

Transcript of interview: <https://autismpersonalcoach.com/surgelinks-25985/>

High Functioning Autism: From Shame to Empowerment *PODCAST*. Interview with Tiffany Joseph, a black autistic AAC user who blogs on race, disability, AAC and more. Episode 41 of Two Sides of the Spectrum.

<https://learnplaythrive.com/podcasts/41-high-functioning-autism-from-shame-to-empowerment-with-tiffany-joseph/>

Website:

NCAPPS – National Center on Advancing Person-Centered Practices and Systems -

<https://ncapps.acl.gov/home.html>

Articles:

Believing in Nonspeakers and the Right to Communicate: An Interview With Dr. Vikram Jaswal. "Of course, there is much more research to be done. But access to communication is a fundamental human right, affecting everything from educational opportunities to the ability to participate in medical decision making. I believe we should be supporting folks to learn to communicate in as many ways as they can."

<http://www.thinkingautismguide.com/2022/03/an-interview-with-dr-vikram-jaswal.html>

Communication Barriers Faced by AAC Users in Accessing Health Care. By endeavor* corbin. November 19, 2021. "Not having a way to produce an audible "NO" or "STOP" makes someone incredibly vulnerable; in a medical setting, it is terrifying... There will always be things I need to say a certain way, and times I can only say things one way. If I don't have autonomy over that choice, whatever authority took it away now has almost infinite power over me."

<https://communicationfirst.org/guest-blog-communication-barriers-faced-by-aac-users-in-accessing-health-care/>

Evidence of authorship on messages in facilitated communication: a case report using accelerometry. By P. Faure, T. Legou, and B. Gepner (2021). *Frontiers in Psychiatry*.

<https://www.frontiersin.org/articles/10.3389/fpsy.2020.543385/full>

Perspective: Presuming Autistic Communication Competence and Reframing Facilitated Communication by Melanie Heyworth, Timothy Chan, Wenn Lawson (2022). *Frontiers in Psychology*.

<https://www.frontiersin.org/articles/10.3389/fpsyg.2022.864991/full>

Project AIM: Autism Intervention Meta-Analysis for Studies of Young Children. Sandbank, Cassidy et al. (2020). *Psychological Bulletin*. The researchers conducted a comprehensive systematic review and meta-analysis of interventions designed for young children with ASD. Comparing group studies examining behavioral, developmental, naturalistic developmental behavioral intervention [NDBI], TEACCH, sensory-based, animal-assisted, and technology-based interventions, they found that there were significant positive effects for behavioral, NDBI, and developmental approaches only. When their analysis was restricted to randomized controlled trial studies (the gold standard in quantitative research) they found positive effects for NDBI and developmental approaches only. <http://dx.doi.org/10.1037/bul0000215>



MAY

Posted on 'Art for Autism' website

POEM and explanation –

May today be awake
 May today be awake with scent
 May today be awake with the scent of flowers
 May today be awake with quality
 May today be awake with the quality of motion

May tomorrow be awake with time
 May tomorrow be awake with the reality of time
 May tomorrow be awake with touch
 May tomorrow be awake with the touch of zero

Awake with the scent of Flowers:

Flowers have a beautiful scent that awakens the senses. The senses are core to human experience. Flowers grow to show us the beauty of life on earth.

Awake with the quality of motion:

Motion is a core universal power that pulls gravity, the solar system and other components to line up a quality of experience that is unparalleled in comparison to anything else we know.

Awake with the reality of time:

Time is a never-ending illusion of human life. We go about our day assuming we understand time, but it is a mystery of the universe. We humans are too lost in this mystery. Enough said.



Awake with the touch of zero.

Infinity is zero point. It's a radical way of looking at the universe. At infinity or zero point, we are creation. We are infinite. Everything outside of the zero point is illusion or maya. There are not enough words to explain the phenomenon of how the universe works. The proof for this is in the pudding, -By Meghana and Chetan Junnuru

We go by the brand name 'Autism Sibs' and maintain a blog site (www.growourjoy.org) to express our joy for writing. Our goal is to share our story, our inner thoughts and progress with as wide an audience as possible.

Tracy Thresher • Disability Rights Advocate • rightsrus@wcmhs.org



For more information about Tracy's travels and ongoing advocacy work please visit:

WALKING THE TALK OF PRESUMING COMPETENCE

<https://ddsd.vermont.gov/walking-talk-presuming-competence>

Intelligence Magnified Through Facilitated Communication Training

<https://www.wellspringguild.org/>

WRETCHES AND JABBERERS

<https://www.wretchesandjabberers.org/>

For more information about the Vermont Department of Aging and Independent Living's Commitment to Communication Choice and Facilitated Communication please visit:

<https://ddsd.vermont.gov/dails-commitment-comm-choice-and-fc>

For more resources on the Right to Communicate please visit:

UNITED FOR COMMUNICATION CHOICE

<https://unitedforcommunicationchoice.org/>

EVERYONE COMMUNICATES!

www.everyonecommunicates.org/why.html



Resources

Accessibility:

Removing Barriers to Healthcare: A New Era for House Calls? November 2021. By Nicole LeBlanc

<https://ncapps.acl.gov/docs/Resources/Removing%20Barriers%20to%20Healthcare%20A%20New%20Era%20for%20House%20Calls%20Accessible%20Edited.pdf>

Supporting Virtual Meeting Accessibility By Nicole LeBlanc

https://ncapps.acl.gov/docs/SupportingMeetingAccessibility_NCAPPS_200519.pdf

Books by Autistics:

A Long Walk Down a Winding Road: Small Steps, Challenges, & Triumphs Through an Autistic Lens by Sam Farmer

<https://www.amazon.com/Long-Walk-Down-Winding-Road-ebook/dp/B07YN65FQX>

Nate's Triumph: Presuming Competence And The Fight For Inclusion by Nate Trainor

<https://www.amazon.com/Nates-Triumph-Presuming-Competence-Inclusion-ebook/dp/B09HR8NBV4>

Shouting at Leaves by Jennifer Msumba. "I have lived through some horrible experiences, all in the name of treatment. But there was one thing I never let those people steal from me, and that was my spirit."

<https://www.barnesandnoble.com/w/shouting-at-leaves-jennifer-msumba/1140138005?ean=9781098399078>

Autistics on Autism: Stories You Need to Hear About What Helped Them While Growing Up and Pursuing Their Dreams Edited by Kerry Magro (February 2022). Many of the stories in this book are from applicants for scholarships from Dr. Magro's nonprofit, KFM Making a Difference.

<https://www.amazon.com/Autistics-Autism-Stories-Growing-Pursuing/dp/B09RTYHNQS/>

Communication:

Recent Reviews of Facilitated Communication Mislead Policymakers by Cathie Davies

https://www.academia.edu/38797833/Recent_Reviews_of_Facilitated_Communication_Mislead_Policymakers

Why Are You Using Picture Exchange Communication System (PECS)? Jane Farrall:

"I don't use it anymore. The evidence base for autistic children is much stronger for all other forms of AAC – and that's what I use." Jane Farrall Consulting (2021, August 21).

<https://www.janefarrall.com/why-are-you-using-picture-exchange-communication-system-pecs/>

Young people explain communication - Ambitious about Autism

https://youtu.be/o_NbDdBq0pU

Education:

The Significance of Involving Nonspeaking Autistic Peer Mentors in Educational Programs By Samuel Capozzi, Dillan Barmache, Emma Cladis, Edlyn Vallejo Pen˜a, PhD, and Jodie Kocur, PhD. Autism in Adulthood, Volume 1, Number 3, 2019

<https://www.liebertpub.com/doi/pdf/10.1089/aut.2019.0006>

Neurodiversity-Affirming Versus Ableist Practice with Transition-Aged Clients. By Jacklyn Googins (MSOT), Greg Boheler (MSOT), Monica Ren-Wen Huang (MS, OTR/L), Sarah Selvaggi Hernandez (MS, OTR/L), Kathryn L. Williams (PhD, OTR/L), and Amy Laurent (PhD, OTR/L). FREE download at Teachers Pay Teachers (site registration required for login).

<https://www.teacherspayteachers.com/Product/Neurodiversity-Affirming-Versus-Ableist-Practice-with-Transition-Aged-Clients-7178751>

Employment:

Disability Employment & Being Person-Centered in the New Normal By Nicole LeBlanc. "In celebration of National Disability Employment Awareness Month (NDEAM), Nicole LeBlanc reflects on the critical need for people with disabilities to have full access to employment and community inclusion opportunities as they recover from the COVID-19 pandemic."

https://ncapps.acl.gov/docs/Resources/NCAPPS_NLeBlanc_NDEAM2021_Final_Accessible.pdf

National Center on Advancing Person-Centered Practices and Systems. Technical Assistancess, Resources, Learning Collaboratives, Webinars, NCAPPS Shorts (videos)

<https://ncapps.acl.gov/>

Neurodiversity in the Workplace – Employer Assistance and Resource Network (EARN) on Disability Inclusion.

<https://askearn.org/page/neurodiversity-in-the-workplace>

Neurodiversity Inclusion: Checklist for Organizational Success by the Employer Assistance and Resource Network (EARN)

https://production-askearn-org.s3.amazonaws.com/EARN_2021_Checklist_Neurodiversity_Inclusion_554271ecee.pdf

APSE – Association of People Supporting Employment First

<https://apse.org/>

Facebook Group for Parents of Autistics:

Ask Autistic Adults – Resource for Parents of Autistics – Facebook group (started in 2018). “This is a resource for parents of autistics, where you can get advice, ask questions, hear stories and perspectives, and get additional resources from actually autistic people.” Note: There are 10 rules for participation once accepted into the group.
<https://www.facebook.com/groups/2138776736451241>

Person-Centered Practices:

Autism Checklist of Doom: Common issues that cause autistic distress, and might be ignored, “treated,” and/or cause a meltdown. By Shannon Rosa and Autistic Science Person. “This checklist is for all autistic people, whether they can speak or not, and whether they have intellectual disability or not. That doesn’t mean every item will be appropriate for every autistic person; you can look through it and see which things might apply. The list is also not meant to be comprehensive; we will probably add more items in the future—and welcome feedback—but we had to stop somewhere.”
<http://www.thinkingautismguide.com/2022/01/autism-checklist-of-doom.html>

Mental Health Therapy with the Autistic Client: Virtual Training for Clinicians by Judy Endow, Sharon Hammer, and Lisa Hoeme
<https://www.autismgreaterwi.org/mental-health-therapy-with-the-autistic-client/>

NCAPPS – National Center on Advancing Person-Centered Practices and Systems - Resources on Education and Awareness, Technical Assistance and Training, Policy and Research, Quality and Service Delivery
<https://ncapps.acl.gov/resources.html>

Autistic person' and 'person with autism' are not one and the same By Sam Farmer
<https://thehill.com/changing-america/opinion/580597-autistic-person-and-person-with-autism-are-not-one-and-the-same>

For Whose Benefit? Evidence, Ethics, and Effectiveness of Autism Interventions. ICDL and Autistic Self Advocacy Network.
<https://autisticadvocacy.org/wp-content/uploads/2021/12/ACWP-Ethics-of-Intervention.pdf>

Safety and police interactions

Morénike Giwa Onaiwu - Good Cops Know That #BlackLivesMatter
<https://morenikego.com/good-cops-know-that-blacklivesmatter/>

Morénike Giwa Onaiwu - "They Don't Know, Don't Show, or Don't Care": Autism's White Privilege Problem

<https://www.liebertpub.com/doi/10.1089/aut.2020.0077>

Dennis Debbaudt website

<https://autismriskmanagement.com/>

Listen to the Voices of Autism 2020 Public Service Announcement – Debbaudt Legacy Productions (4:03; captioned)

https://www.youtube.com/watch?v=SL_0yV-lciQ

Dennis Debbaudt Teaches First Responders About Autism (3:14)

<https://www.youtube.com/watch?v=35DAZ9GHJ0>

Dennis Debbaudt - Autism Safety - Part 1 (9:36) and Part 2 (9:19)

<https://www.youtube.com/watch?v=mRAvGTfGZug>

<https://www.youtube.com/watch?v=ID229QSQJYI>

The following three items are resources that the University of Connecticut's Center for Excellence in Developmental Disabilities Education, Research and Service (UConn UCED) provides to people with disabilities to use in sharing information with the first responders in their communities, particularly when meeting them before a crisis.

A Communication Aid for Emergency Personnel

https://uconnuccedd.org/wp-content/uploads/sites/3346/2021/08/Final-Communication-Flipbook-revised-2_13_2020.pdf

Tips for Emergency Personnel: Supporting People with Unique Access or Functional Needs – PREP IS PERSONAL

<https://uconnuccedd.org/wp-content/uploads/sites/3346/2021/08/Original-Flipbook-final.pdf>

Microsoft Word - PREP IS PERSONAL CHECKLIST.docx (uconnuccedd.org)

<https://uconnuccedd.org/wp-content/uploads/sites/1340/2015/06/PREP-IS-PERSONAL-CHECKLIST.pdf>

One fine day
a young girl did not speak
and she lost her voice.

Love was only a short while away but out of reach.

Perfectly formed but waking to a new reality was this girl's dilemma.
Trying to save her body from destruction was all she could do to put
up

with

the world.

Please answer why this happened to
such a sweet girl.

She had reached the point of
despair when there was one person
who offered a way out.

It was life-changing to leave behind
her screaming and her slapping.

She could finally say the things
that were muddled in her brain.
She was free once more.

—Mya Lawrence



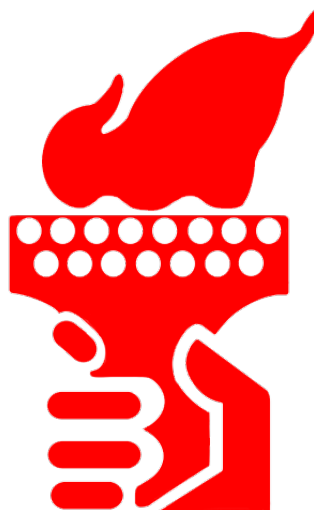
Mya Lawrence is a 14 year-old autistic girl (she/her) who lives in Londonderry, NH. She began typing to communicate in 2020, and loves math and Shakespeare. Mya wants to become a math teacher and work with autistics like herself. She especially wants to become a voice for those who have none. She is passionate about the right to communicate.

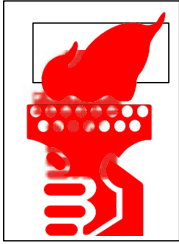


Principles of the Autism National Committee

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).



Name _____

Address _____

City _____ State _____ Zipcode _____ Phone _____

Email _____

Newsletter by email ___ or in printed form when available ___

I want to _____ Renew my membership _____ Become a member

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

_____ Student _____ Professional (field) _____

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

_____ \$30.00 (regular membership) _____ \$10.00 (student membership)

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

Send this form or a copy and a check payable to Autism National Committee to
 PO Box 115 Oberlin, OH 44074

AutCom Officers

Lisa Keller, President
 Judy Bailey, Secretary
 Sandra McClennen, Past President

Autism National
Committee PO Box 115
Oberlin, OH 44074



Time to Renew or Join Today!

Annual membership begins in January

Membership form on Page

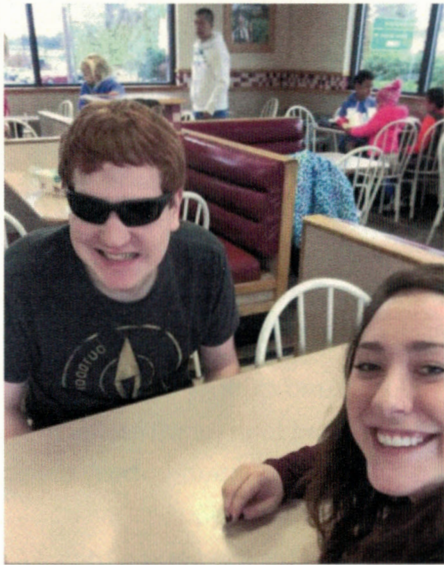


The Communicator

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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The COMMUNICATOR Committee
Judy Bailey
Karen Mirochna
Alan Kurtz



Ian Nordling and his communication partner Gina Conger in the community

Who We Are

About Us

My name is Ian Nordling and I am an autistic. I am writing this brochure in hopes that law enforcement can identify and handle an interaction with autistics successfully and safely. Making our community more inclusive is very important to me. I was without means of communication most of my life it was during this time that I had a scary interaction with law enforcement. I want to make it easier for the youth in my situation, so they do not experience the same things I have. Thank you for taking the time to read this.

Special thanks to....

The Mayor for accepting me into the Herndon Youth Advisory Committee

The other students on the committee

The parents for their support

The Police Department and Police Chief for having this meeting and making the time to form relationships with the youth in our community

To my parents for their love and support

My communication partner for helping me put this brochure together

-Ian Nordling

Created by:
Ian Nordling
and Gina
Conger

**INFORMATION FOR
FIRST RESPONDERS
DEALING WITH
AUTISTICS**
Herndon, VA
2018

AUTISM

Persons with autism may possess the following characteristics in various combinations and in varying degrees of severity.



INFORMATION FOR FIRST RESPONDERS DEALING WITH AUTISTICS

*A guideline to making every
interaction successful*



"Police are the backbone in every community"- Ian Nordling

A guide to interactions with Autistics

Why we chose to make this...

"It is important that police are trained on Autism. Having been in a situation with police myself, I know how important this training is. I was so scared to be in trouble. From a personal standpoint it is critical that officers know how to work with Autistics in an emergency. Protocols for these crisis situations need to offer a viewpoint from Autistics. I am hopeful this guide will shine a light on this issue. Working with autistics can be hard sometimes. Please know we mean no harm.

How to identify someone with Autism

"Identifying someone with Autism is a vital assessment when handling emergency situations. Ian has put together some signs to help identify Autistics." Gina Conger

"A person with Autism might not follow commands"

A person with Autism might...

- Not respond to verbal commands
- Look away from the officers and lights
- Get overwhelmed and look as if they are not following commands
- Run away
- Not speak to the police officer
- Look mad
- Wander into traffic or appear as a nuisance
- Might pace or stand up even when advised not to

Autism

How should a first responder approach an Autistic...?

- Slowly and calm
- Listen and look for stressors such as lights, sounds, busy areas
- Give clear directions
- Give time for the person to respond to the commands
- Most importantly, be patient

How should the Officer interact with individual...?

- Do not touch the person
- Do not yell at the person, instead try using a firm but friendly tone
- Be on the lookout for a person who may be having a meltdown or sensory overload
- Look for signs of escalating anxiousness
- Give parents a careful warning