



Volume 24, No. 1 - Winter 2018

THE COMMUNICATOR

A Publication of the Autism National Committee



The Communicator on Communication by Judy Bailey, Guest Editor

We are pleased to present this issue marking the return of The Communicator. The theme of this long-awaited issue is communication, with articles and poems by several people on the autism spectrum, along with resources for learning more. We focus on communication, because having a voice and being heard is basic in life. As Anne McDonald said, "Communication falls into the same category as food, drink, and shelter—it is essential for life, and without it life becomes worthless." However, access to communication using methods that one finds effective for oneself is not assured to all. Many myths exist about communication, and they create barriers for people who have little or no reliable speech, sometimes called "nonspeaking". Although some people mistakenly view speech, however limited, as superior to other methods, a friend who types to communicate shared this wise insight, "Communication is more important than speech." We concur with him.

Oftentimes, family and friends are key to accessing methods of communication besides speech, often called "augmentative and alternative communication (AAC)." In fact, their advocacy and support are essential. One therapist put it this way, "Despite the proven efficacy of AAC, an individual's access to AAC services typically depends upon (1) where they happen to live, (2) what their doctor already knows about AAC and (3) how aggressively they, or their family members, seek help from professionals who provide AAC services." (Sarah Blackstone, 2007) Fortunately, more families,

friends, and self-advocates are taking on this work and leading the way. These efforts, along with advances in technology, teaching methods for literacy and communication, communication partner training, and internet communities are resulting in greater access for more people. Even so, many remain without access, and that must change.

People who use AAC methods are being heard in blogs, books, films, webinars, and online communities. Everyone needs to go beyond wants and needs to express complaints, hopes and dreams, protests, jokes, thoughts, hurts, fears, questions, worries, love, friendship, and more. In short, people need to be able to communicate with anyone, anytime, anywhere, about anything. Short of this, their communication journey is far from over.

We hope this issue of The Communicator will be a helpful resource. Everyone can communicate and everyone can learn to communicate better and better. We must never give up. We must find the ways.

Attention AutCom Members

Consider requesting extra copies of this newsletter in print to share with your legislator, DD Council, local Arc chapter, families who might want to join AutCom, your child's teacher, and others. Email Barbara Cutler, bccutler@aol.com, to request additional copies. Be sure to include your mailing address.

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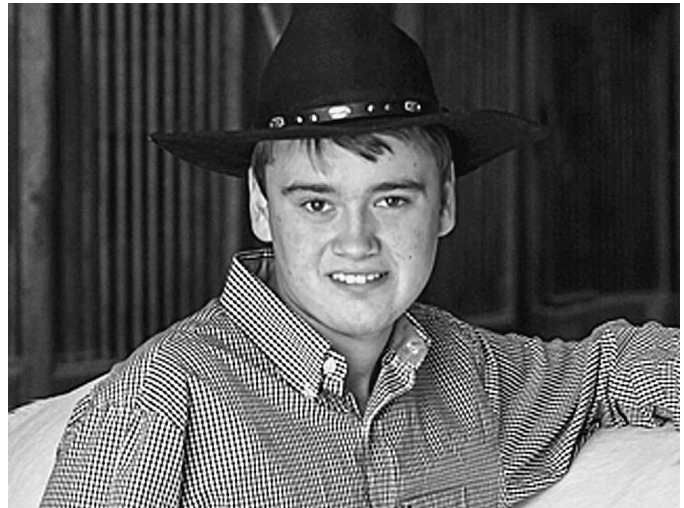
Judy Bailey – Guest Editor & Long Time AutCom Member

Judy C. Bailey (M.Ed., PBSF) a long-time AutCom member, recently joined the AutCom Board and is serving as Guest Editor for this issue of The Communicator. She has worked for many years providing services, consultation, and advocacy in various methods of communication that involve pointing, typing, and spelling to communicate (including Facilitated Communication Training and Rapid Prompting Method), and also in supported employment, positive behavior supports, and literacy. She serves on various committees and boards (TASH, Virginia TASH, Nonspeaking CommUnity Consortium, Annual 24-Hour International AAC Chat). Her all-volunteer nonprofit project, Everyone Communicates, provides information on and advocacy for access to effective communication for all using methods of their choice throughout the lifespan. (website www.everyonecommunicates.org and on Facebook).

New Board Member and Poet

Matt Hayes is an advocate in the Facilitated Communication Training (FCT) movement. FCT uses physical and verbal support to bring communication to individuals who are speechless. Autistic from birth, Matt began communicating at the age of five through Facilitated Communication Training, an alternative and augmentative form of communication. At age 6, he wrote his first poem, "Trapped in Silence." A member of the Saint Louis Poetry Society since the age of 15, he is an active participant in their writers' workshops. Currently the subject of a PBS documentary, "My Voice: One Man's Journey to Overcome the Silence of Autism," Matt is eager to build bridges between autists and neurotypical individuals everywhere. His primary writing focus is poetry. Reading the works of poets eager to expand the boundaries of their craft is both his inspiration and challenge.

Matt has spoken at Yale University, presented his work as the featured guest poet at the Telluride Talking Gourds Poetry Society, been interviewed on KOTO radio, presented at various autism conferences and communication workshops, and regularly contributes critiques to various published poets. He currently collaborates on a forthcoming book of friendship tentatively titled "The Possibility of Joy." After years of dedicated practice, Matt is now nearly independent in his typing and is able to speak what he types. A sunshine and water fan, Matt splits his time between a tiny Lake Erie island and his native Saint Louis, Missouri. (Matt Hayes Headshot © Alex Kendall Photography)



Matt Hayes

Blows of Destiny Reined Tightly and Crossed with Swords by Matt Hayes, December 1, 2017

Masticated,
barren waste
of the soul-filled
outer space,
living beings
castigate
the silent daring
saved by fate

nature plunks
a fiery face
into the silent,
looming race -
talking with

a simple row
of letters
set up in a tow

in spite of how
it seems to rage
the talkers on
their guilty stage,
the words that
pointing ushers in
is given weight
by the men

who field their doubts
and biggest lies,
that pointing is
a needed tie
to pictures on
an empty page
grafted by
a talking page.

Blogging, Community, Activism by Amy Sequenzia Presented at AutCom 2013 Conference



Amy Sequenzia

Note: My presentation was interactive, with power point and participation from the audience. My computer “spoke” the words I typed, complementing what was in the power point. This text is what I presented, with a few changes for better comprehension (and some editing for length).

I will start with the definition of blogging: The act of writing opinions and ideas on a regular basis. To me it is also a way to connect, to learn and to educate.

I blog because

- I have a voice and I want to be heard.
- My community embraced me and my words, and I am part of a movement that is proud and loud.
- I have loud hands.
- I believe everybody has something to say, and blogging is how I say it better.
- I am an activist and I believe changes happen only through action. Blogging is part of my activism.
- Being social with a lot of people in one room is hard for me. Having many virtual friends allows me to ease my anxiety and makes it easier for me when I meet them in real life.
- Words are beautiful.

I started blogging by accident. I did not know I wanted to be so loud. But my fingers did not accept a quiet existence, just as my brain would not accept locking

my thoughts in, and I decided to listen. All the ideas I had composed in my brain would soon find their way through my fingers to the web.

It all really began when I saw people moving like me, communicating like me, people who needed almost the same amount of support I do. I saw Sue Rubin and I saw Amanda Baggs. The name of Amanda’s blog says why blogging, community and activism are connected. Amanda (now Mel Baggs) wrote: “The name of this blog means “ballast-existence” (<https://ballastexistenz.wordpress.com/>) It was once widely used in anti-disability propaganda to try to weed us out of the human race entirely. The reason I titled my blog this is to highlight that I’m fully aware that I and many others still hold that status in many people’s minds, and to expose that kind of hate for what it is. I don’t believe in ballast-existences. But most people so labeled, even those presumed to be unaware of it, become well aware in some way or another that we are regarded as useless ballast to be tossed away if possible.”

Something else caught my attention: the Autistic Self Advocacy Network (ASAN) video “No Myths” - <http://www.youtube.com/watch?v=CabAn6yeJXU> I saw Autistic people saying that the conversation about autism must include us. I learned that the community I would soon join was effecting change, sharing information, sharing feelings, educating. This was happening through blogs, videos and campaigns.

When I met Ari Ne’eman (who founded Autism Self-Advocacy Network – ASAN), he suggested that I started writing letters to the newspaper. I did that, I joined Facebook, I met other autistic writers. I was reading and sharing information. I was learning.

I noticed that most of my friends reject “functioning” labels. That’s when I decided to write my first blog post, “Non-speaking, ‘Low-functioning’”. It was published on the Shift Journal and it went viral - <http://www.shiftjournal.com/2012/01/11/non-speaking-low-functioning/> Here is a quote from the article: “All the labels given to us only help make myths seem like the reality. By classifying non-speaking autistics as low-functioning, one is lowering expectations for the autistic individual. He or she is not given a chance to express himself/herself and maybe show hidden abilities.”

I need to write because words dance in my head,

(Continued on next page)

they form sentences and thoughts are born. I have to put on the screen what my brain sees. We have been, and still are, kept out of the conversation about us. Blogging allows us to share and spread the information we want more people to hear when we are not allowed in the mainstream forums. Sometimes we blog as a community and we organize ourselves around one common goal.

That's activism through blogging, on behalf of our community. My community is made of an awesome group of people. They are mostly autistics and disabled, parents and allies, people who believe we all have things to say, people who presume competence, people who know we are all worthy. My community is neurodiverse and we are activists. We also believe that autistic culture is real.

When my first article was posted, I had a few friends on that virtual place that we love and hate: Facebook. I joined it because I wanted to know what other autistics were saying. I soon realized that there were a lot of blogs with a lot of information, and that activism was something one could start online.

After some people read my article and shared it, many others were curious about me. Ollibeau (<https://ollibeau.com>) ask me to blog. Autism Women's Network (<http://autismwomensnetwork.org>) did too. Curiosity became respect and eagerness to listen to, or read, my typed words. All this was possible because the neurodiversity community, especially the autism community, embraced me as equal, as an important voice in our fight for inclusion and acceptance. How could I not become an activist?

I knew about some of the things autistics were protesting; I knew about some of their victories; I disliked Autism Speaks rhetoric as much as they did. Those are some shared beliefs. Here are two examples of successful protests: The ransom notes campaign and the "I Am Autism" video, taken down and getting an autistic friendly version "I Am Autism Speaks" (<http://www.youtube.com/watch?v=yU2paLv1MGE>)

But as great as it is to have many voices with one goal, those pioneers were dismissed as not autistic enough, they were told that they were too "high-functioning" to understand how tragic the lives of "low-functioning" autistics were, what a burden they are for the families. That was like an official invitation to debunk myths. Enter Amy, a proud, very disabled, independent thinker, with an uncooperative body, happy autistic. I am not a tragedy, not a burden, and not the only one who can crush labels with words. I have a rich, fulfilling life. As I like to say: I will word-butt with the naysayers until they lose all their old

and tired arguments. Because they will lose those arguments.

I never expected to be an activist. I was told that I couldn't do things other advocates did because I was too impaired, because I did not have the life experiences autistics "less affected" did, because I should simply self-advocate for what affected me directly. But what affects my community affects me. If one of us is ignored, disrespected, dismissed, murdered, it affects all of us. We are very diverse, but when one of us succeeds, it opens a door for others. When one of us breaks stereotypes, it is good for us all. We need to pay attention to the conversation about us, embrace all who believe we are worthy, try to educate those who still don't see our humanity and claim our place in this world. Just the way we are.

I wrote an article about why I chose to be called an activist instead of self-advocate. I changed how I refer to myself because what I do is no longer only about me. It is about my community and about future generations of Autistics. I am not only fighting for autistics who look a lot like me, or only for autistics that are non-speaking. I must know and understand what supports ALL my brothers and sisters want and need. (<http://autismwomensnetwork.org/node/1597>)

We should learn about the Disabilities Rights Movement and about all that involves our lives and who we are. We should participate. And when I say "we" I mean ALL of us. (<http://autismwomensnetwork.org/node/1592>) Do you remember what happened when Congress set up a hearing to discuss autism? They did not invite any of us. We came together to demand the inclusion of autistics. Petitions and letters are a form of activism. Two Autistics were invited, last minute. But they were there and they spoke. You can see a video of Ari Ne'eman at the hearing - <http://www.youtube.com/watch?v=BkGr2JPUbVc>

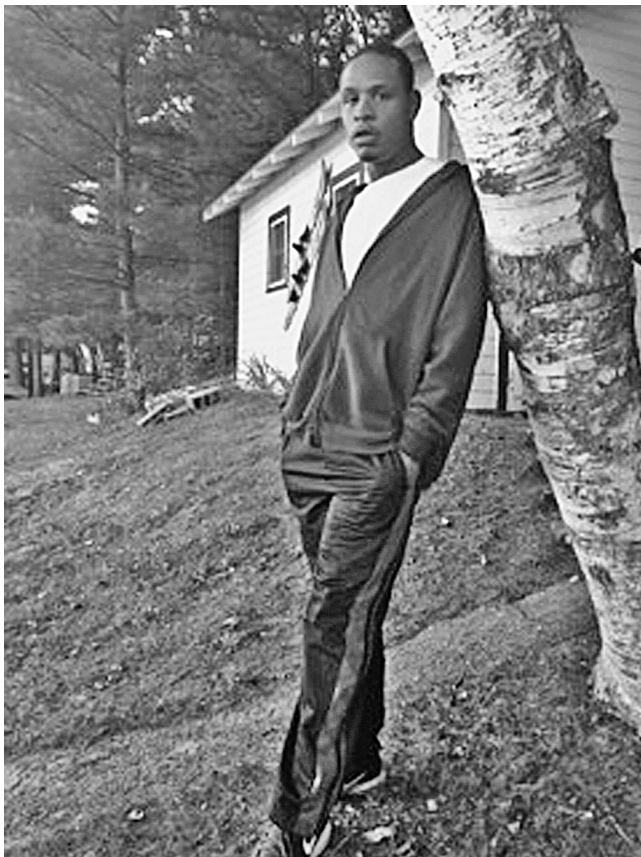
Other forms of activism are Blogs and Flash Blogs. When Google decided to change its algorithm for auto complete in searches of "autistic people are" and "autistic people should", it was because bloggers decided to write articles with positive messages about autistic people and share all the articles in one place, on the same day (<http://autisticpeoplesould.blogspot.com/p/postroll.html>, <http://autisticpeopleare.blogspot.com/p/postroll.html>) We should all be activists. We can only bring about changes if we participate. And we can all contribute, in our own way.

My blog has links to all my articles, interviews and poems published online. <http://nonspeakingautisticspeaking.blogspot.com>

If you are not a member, now is the time to join.

Congratulations DJ!

DJ Savarese (pictured to the right) graduated Phi Beta Kappa from Oberlin College in May 2017 with a double major in Anthropology and Creative Writing. An ASAN Scholar Fellow, he was also the recipient of Oberlin's William Battick Poetry Fellowship and their Comfort Starr Award for meritorious scholarly work in Anthropology. As a writer, he has published poems and prose in *The Iowa Review*, *Seneca Review*, *Prospect*, *Disability Studies Quarterly*, *StoneCanoe*, *wordgatherings.com*, and *Voices for Diversity and Social Justice: A Literary Education Anthology*. He is currently fully employed as a 2017 Youth Exchange/Human Rights Initiative Fellow, working to make literacy-based education, communication, and inclusive lives a reality for all nonspeaking people. To see some of his work, visit his website: www.djsavarese.com.



Anthony Brown

I am a nonverbal man. I am twenty eight years old. My poems were written using supported typing. Some of the time, I had support. Other times I typed as my partner held the keyboard. My interest is in educating others about partnered communication.

Spirit Rising

Empty hearts, redeeming grace
 Light within, often dim
 Healing feeling people
 Through our heartfelt ways
 Remember kindness, remember joy
 No moping time for me
 Time too short, to waste a day
 Hopeful heart is key
 More than wanting
 Exciting times
 Shifting frequency
 Mending hearts
 Relieving pain
 Very busy now

Eagles Landing

Dreaming thoughts of freedom
 Seeing end in sight
 Making progress daily
 Dreaming day and night
 Seeing my vision clearer
 Than I ever have before
 Feeling more connected
 Centered in my core
 Earth reaches up to me
 Wraps me in her arms
 Enamored like an eagle
 By her magnetic charms
 Feeding my soul with wonder
 Of what I missed before
 Great adventures await me
 In this new domain
 Vibrational shift occurring
 Nothing seems the same

FC, Rob and Me

by Barbara Cutler

When Facilitated Communication (FC) first arrived in the States, I was interested but planned to wait for some validation before trying FC with my son, Rob. My plans were interrupted when Michael McSheehan of UNH, sent by Anne Donnellan and Herb Lovett, arrived at our door. He came to introduce Rob to FC, and we could not say No.

Michael respectfully introduced himself to Rob and Rob seemed willing to try to use Michael's keyboard. He typed his name with Michael's support and a few more words. Rob then pointed to a magazine's cover with a picture of the world, and slowly and intently began to type.

I GREATLY FEZAR THE RUIN OF THE EARBTH
UNLESS HUMANS JKM JOINTLY DISCOVER ITS
CYURE

Rob continued to type with Michael

I FEEL BETTER NOW I CAN DO THIS I VERY
OFTEN DON'T SAY WAT I WANT.

PBS cleaned up the typos for its anti-FC program which opened with

I GREATLY FEAR THE RUIN OF THE EARTH
UNLESS HUMANS JOINTLY FIND A CURE

and scoffed at the idea that an autistic person was capable of producing such a statement.

Watching Rob produce this statement, we were overwhelmed. He was already over 35. Had he been waiting years to share this concern with someone? Anyone? He did not tell us he was smart, or he loved us. That would come later. He was a man with a mission: to advocate.

This first statement was consistent with Rob saving everything. It was because of FC that he could talk about recycling. Almost nothing went into the trash can: plants and leaves back to the earth, crumbs to the birds, paper, even small pieces, into the recycle bin. Nothing was too small to recycle. This was just the beginning of his work which extended to advocating for autism, disabilities and then to troubled youth. No one should be forgotten.

But first he had to become competent with FC. He showed us he could type with Michael, but could he type with staff? We followed Michael's directions to practice "set work" to enable Rob's staff Mark to support Rob. Every weekend Rob practiced, but we got a word here and there and the rest a mishmash of letters. Two years later we were only getting simple answers to questions, yes, no, one word, a phrase. Mark and I felt we were going nowhere and were ready to quit. But Rob would not allow that. Every weekend Rob said, "Type!" in a way that meant if we did not type, there would be trouble. And so we typed. He persevered and we followed. One day, we must have been looking at maps. Rob typed with staff facilitating:

I LIKE TO GO TO GERMANY.

I asked if he remembered Germany and he spontaneously typed:

I WAS 3 YESR AOLD I PULL IN YOUR UION
STATION

I knew we had a real breakthrough. He was referencing a stressful trip in Germany about which staff had no knowledge. UION referred to the train we took. I went on, "Do you remember the mountains in Austria?"

HIKE IN MOUNTAINS WE RIDE INTO RIORT TO
AUSTRIAN IW GO TO RILUR

Not perfect, but these were spontaneous words he chose to represent a real event that only he and I knew. After more than two years of practice, we were finally on our way.

In just four months he became fluent – grammatically correct, always a perfect speller, spontaneous communications, always facilitated by staff who were supporting him but not participating in the conversation. The conversation partner was often me, but also his counselor, friends, people at meetings and conferences, and constantly changing groups of troubled youth.

Rob was now able to attend and participate in conferences, state and local citizen advisory boards, serve as AutCom's first autistic President, publish articles, write letters of thanks and condolence — the many ways that language connects us. He could direct his medical care, his staff, participate in planning, share his feelings with friends and family (and political figures), and submit testimony to the Supreme Court in the Olmstead case.

Over the years he was supported in FC by several people, but never me. He made clear that was his choice. I was to be one he talked to.

FC showed that Rob was not only smart but he was a man of courage (at NIMH):

WHY IS BEHAVIORISM, PAIN, ADVERSIVE
TREATMENT RUNNING WILD IN AUTISM
TREATMENT? WHY IS SHAME AND PAIN USED?
WHATEVER HAPPENED TO HUMAN RIGHTS
FOR ALL,NOT SOME?

Compassion (at Medicine Wheel)

EACH WEEK I WORK WITH SIX YOUNG MEN
IDENTIFIED BY STREET WORKERS AS THE
MOST LIKELY CANDIDATES FOR PERPETRATING
VIOLENCE OR BEING VICTIMS OF VIOLENCE.
I TELL THEM HOW PROUD I AM OF THEM TO
WANT TO GET CONTROL OF THEIR LIVES.

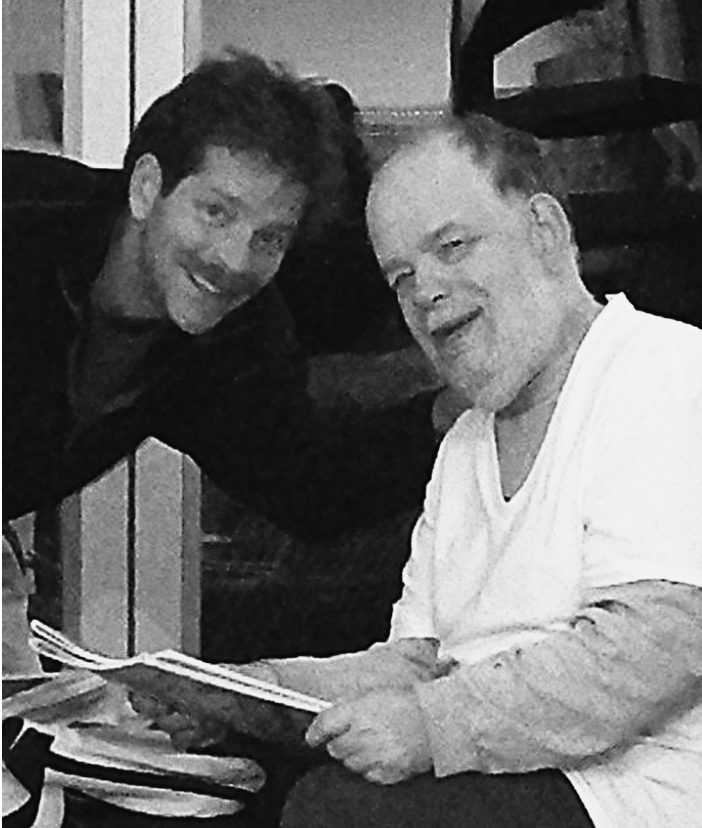
Caring (to Bonnie)

LIFE IS GOOD NOW. I FEEL WE WERE MEANT TO
BE FRIENDS FOR LIFE. I THINK WE CAN GROW
OLD TOGETHER. YES.

Humor (annual RV trip)

THANK GOD GEORGE ORGANIZES THESE
TRIPS. OTHERWISE WE WOULD PROBABLY
NOT MAKE IT OUT OF ARLINGTON.

I thank God, Herb Lovett, Anne Donnellan and Michael McSheehan for freeing my son from a life of isolation. No longer is Rob a prisoner of silence. We are blessed.



George and Rob Cutler

Ask Rob 2017

Q: What did you tell Dr. Bill Condon when he said “If you could tell people about your delays and your world it would help us very much to help others who cannot tell us these things.”

A: People with autism feel alienated because sometimes we want to be alone. Many typical folks say that we are going into our own world, but really we just need a break from life’s challenges.

I have stress just for being autistic. Movement and sensory issues need to be looked at. I have a body that tremors. I hope that my tremors are from stress and not from seizures. Mystery is only a new challenge.

We want the freedom to go at our own speed, not the speed behaviorists decide. I voice the need to move more fluently.

We cannot always control the way our bodies move. My body tremors but my mind is sharp. My hands are my voice, and a helping hand is better than not having the opportunity to speak. It is hard for me to talk. I feel pain in my head when I am asked to talk a lot.

FC has opened a whole new world to me. Access to FC should be a top priority in advancing our acceptance.



Niko Boskovic

Niko Boskovic

About Niko Boskovic (<https://www.facebook.com/pg/nikoboskovicPDX>):

Niko Boskovic is a 16 year old from Portland, OR who is passionate about autistic people’s rights. He began attending a gen ed high school in 2015 after being homeschooled and attending an ABA program since age three, and is on track to receive an Oregon diploma in 2019. He plans to study science in college.

Niko’s life was transformed after he learned to communicate using a letterboard three years ago. Now he wants to apply his energy to changing the world to be a better place for people who aren’t verbal. Niko believes he is part of a civil rights movement that will have a profound impact on American society, and is writing a book about his experience being autistic. Here’s what Niko has to say in his own words:

WHAT MOST PEOPLE DON’T KNOW ABOUT ME IS THAT I HAVE BEEN ACTIVELY WRITING MY THOUGHTS FOR AS LONG AS I CAN REMEMBER. BEING NON-VERBAL, I’VE HAD TO DEVELOP A WAY TO WRITE DOWN MY THOUGHTS AND STORE THEM

(Continued on next page)

AWAY UNTIL I HAD A MEANS TO COMMUNICATE THEM. I'M NOT EXAGGERATING WHEN I SAY THAT I HAVE TOMES OF THOUGHTS STORED AWAY IN MY MIND. THE MOST FRUSTRATING THING, ASIDE FROM NOT BEING ABLE TO COMMUNICATE INDEPENDENTLY, IS NOT HAVING THE MEANS TO SHARE EVEN ONE PERCENT OF MY THOUGHTS, BECAUSE IT TAKES SO LONG TO SPELL EVERYTHING OUT WITH THE LETTERBOARD.

YOU MIGHT THINK I SHOULD BE GRATEFUL FOR THE LETTERBOARD - AND I AM - BUT NOW I WISH I HAD A WAY TO GET ALL THESE STORIES, HISTORIES, AND OPINIONS ON PAPER. WERE IT AVAILABLE, I WOULDN'T HESITATE TO HAVE SOME TYPE OF TECHNOLOGY IMPLANTED INTO MY BRAIN, BECAUSE IT WOULD ALLOW ME TO COMMUNICATE AS RAPIDLY AS NT'S DO.

THE THING IS, I DON'T KNOW IF THAT TECHNOLOGY IS EVER GOING TO SHOW UP IN MY LIFETIME. BUT I WAITED THIRTEEN YEARS TO FINALLY BE ABLE TO RELAY MY THOUGHTS - WHAT'S THIRTEEN MORE? OR TWENTY, FOR THAT MATTER. BECAUSE I NOW KNOW THAT WE NON-

SPEAKING AUTISTICS HAVE TO STEP UP AND RECLAIM OUR VOICES TO KEEP OTHERS FROM TAKING THEM AWAY FROM US.

YES, THERE ARE SOME WHO MEAN WELL - BUT UNTIL WE, AS A DISCRIMINATED CLASS, FIND THE OPPORTUNITY TO SHARE OUR EXPERIENCES AND CLAIM OUR RIGHT TO SPEAK ON OUR OWN BEHALF, NOTHING WILL CHANGE. YOU HAVE TO FIGHT FOR THAT RIGHT, BECAUSE NO ONE IS GOING TO JUST GIVE IT TO YOU WITHOUT A FIGHT.

MY EXPERTISE IN BEING AUTISTIC SUPERSEDES THE VOICES OF PROFESSIONALS, PARENTS, RESEARCHERS, AND EVEN OTHER AUTISTICS WHO ARE VERBAL. THERE'S AN INTRINSIC VALUE IN ALLOWING US TO SPEAK ON OUR OWN BEHALF, AND WE NEED TO SEIZE THAT POWERFUL RIGHT BACK. AIMING FOR TRUE INCLUSION IS THE GOAL AND THE PURPOSE OF MY TAPPING OUT THESE WORDS DAY AFTER DAY. ALSO, IT KEEPS MY MIND AT EASE TO KNOW THAT SOMEDAY WE WILL ATTAIN IT.

IDEAS TO HELP YOU UNDERSTAND HOW I COMMUNICATE WITH PEOPLE by Jordan Ackerson

- 1) If possible, please let me finish what I'm trying to say rather than jumping in, interrupting, and trying to finish my sentence for me.
- 2) If you ask me a question, please *give me enough time to process* what you asked me so I'm able to give you a clear answer. If you repeat the question too soon, or ask me another question, then I forget your original question and I don't know what to say.
- 3) Slow your pace down when you're talking to me or otherwise my brain can't process auditorily what you said. I don't have trouble hearing. It just takes my brain a little longer to interpret what is being said to me.
- 4) Before changing the topic, it's fine to ask me if I was tracking what you were saying. I will also try to let you know if I am not following you, or if I forget what you were saying.
- 5) Very general questions are harder for me to answer. It would be very helpful when you ask me a question if you could give me choices from which to answer.
- 6) Sometimes I have a tendency to go on talking about one subject a little bit longer than I really need to. If that happens, you have my permission to let me know, in a very courteous way, when you're having trouble listening to me. You can let me know when you're feeling like you are ready to change the topic.
- 7) Even though it takes me longer to process what's being said, that *doesn't* mean that I don't understand what's going on in the world.
- 8) Please understand that it takes a lot of my energy to focus on what's being said to me. If I don't follow what you're saying, that doesn't mean that I'm not trying to listen.
- 9) To let you know, my brain thinks very fast and I can't get words quite as quickly as my thoughts. This sometimes causes me to pant, or to repeat the same words to make sure that people are still listening to me while I'm working getting my words out.

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Renew Your Membership for 2018!

New and Exciting Books, Films and Websites

New Documentary Films:

- My Voice: One Man's Journey to Overcome the Silence of Autism, featuring Matt Hays. Full length documentary: <https://vimeo.com/193191599>
- Deej movie and Inclusion Tour with co-producer D.J. "Deej" Savarese and company. Website: <https://www.deejmovie.com/>
- Unspoken by Emma Zurcher-Long. Trailer: <https://vimeo.com/194066655>

New Books:

- A Doorknob for the Eye by D.J. Savarese <http://www.unrestrictedinterest.com/store/a-doorknob-for-the-eye-by-dj-savarese>
- Anatomy of Autism: A Pocket Guide for Educators, Parents, and Students Kindle Edition by Diego Pena <https://www.amazon.com/dp/B071VMWWL1/>
- Autism: The Movement Sensing Perspective by Elizabeth B. Torres and Caroline Whyatt <https://www.crcpress.com/Autism-The-Movement-Sensing-Perspective/Torres-Whyatt/p/book/9781482251630>
- Living in the Eye: Life With Autism by J. Kevin Vasey <http://www.gloriapearsonvasey.com/kevins-work/>
- Paul and His Beast by Sarah Stup <http://sarahstup.com/shop/paul-and-his-beast/>
- Uniquely Human: A Different Way of Seeing Autism by Barry M. Prizant, Ph.D., with Tom Fields-Meyer <http://barryprizant.com/uniquely-human/>

Websites with Blogs, Books & Films:

(Blogs and other writing by people who use various methods to communicate – additions welcome)

- Everyone Communicates website, Personal Stories section: <http://www.everyonecommunicates.org/stories.html>
- Blogs and websites by people who use AAC to communicate and their parents and supporters <http://everyonecommunicates.blogspot.com/2013/10/blogs-and-websites-by-people-who-use.html>

(Books, Chapters, Poetry, and Articles by Communicators)

- Books, Chapters, and Writings by People Who Use AAC to Communicate: <http://typingtocommunicatebooks.blogspot.com/>

(Films, Documentaries, and Videos by or about Communicators)

- AAC-Related Films, Documentaries, Videos list with links: <http://aacfilms.blogspot.com/>

Thumbs Up and Thumbs Down

Thumbs Up

- TASH Communication for All initiative, TASH Communication Work Group, and TASH 2017 Communication Strand and film screenings (Mr. Connolly Has ALS; Unspoken; and Deej)
- Autistic Self Advocacy Network's (ASAN) "Everybody Communicates: Toolkit for Accessing Communication Assessments, Funding and Accommodations"

Thumbs Down

- ISAAC Position Statement on Facilitated Communication
- ASHA Review Committee on Facilitated Communication (FC) and Rapid Prompting Method (RPM), which excludes self-advocates, parents, and any individuals who have significant experience using or teaching these and related strategies that may lead to spelling and typing to communicate, and which includes a majority of researchers who have published previously against FC and/or RPM.
- Ongoing negative commentary and activities in various media by staunch opponents of the use of FC training, RPM, and similar methods to develop pointing skills to access communication devices both low and high tech; continuing public criticism of and skepticism about people who have worked to improve their communication using these methods and condemnation of all who use these methods to teach people with little or no functional speech and who hear and respect their voices.

Resources

- Anne McDonald Centre, Victoria, Australia, Rosemary Crossley, Director. <http://www.annemcdonaldcentre.org.au/>
- Everyone Communicates - Information, advocacy, and resources on various methods for communication throughout the lifespan. www.everyonecommunicates.org and Facebook
- Facilitated Communication Training book by Rosemary Crossley (free download) <http://www.annemcdonaldcentre.org.au/facilitated-communication-training-book>
- HALO (Helping Autism through Learning and Outreach)– Soma Mukhopadhyay, Rapid Prompting Method. www.halo-soma.org
- Institute on Communication and Inclusion at Syracuse University, Christy Ashby, Director. Facilitated Communication / Supported Typing. www.ici.syr.edu
- Nonspeaking Community Consortium – NCC's mission is to promote access and communication choice for nonspeaking individuals through education, research, and advocacy. www.nonspeakingcommunity.org and Facebook
- Typing to Speak, Inc. Workshops and training in alternative and augmentative communication. <https://typingtospeak.org/> and Facebook
- Unlocking Voices - Using RPM. Rapid Prompting Method. <http://www.unlockingvoices.com/> and Facebook
- U.S. Department of Education, Office for Civil Rights and Office for Special Education and Rehabilitative Services, and the Department of Justice, Civil Rights Division. Meeting the Communication Needs of Students with Hearing, Vision, or Speech Disabilities <http://www2.ed.gov/about/offices/list/ocr/docs/dcl-factsheet-parent-201411.pdf>
- Frequently Asked Questions on Effective Communication for Students with Hearing, Vision, or Speech Disabilities in Public Elementary and Secondary Schools <http://www2.ed.gov/about/offices/list/ocr/docs/dcl-faqs-effective-communication-201411.pdf>
- Wellspring Guild. Facilitated Communication Training / Supported typing. <http://www.wellspringguild.org/> and Facebook



Luke Burke

Luke Burke, age 8, uses a letter board for communication. He is passionate about advocating and educating for those who haven't found their method of communication yet. "I will try always to educate now that I am able to. Want people to accept our differences." Luke's mantra is "presume competence always." His Facebook page/blog is "Different not Less."

Luke's Poem

Words Matter to Me

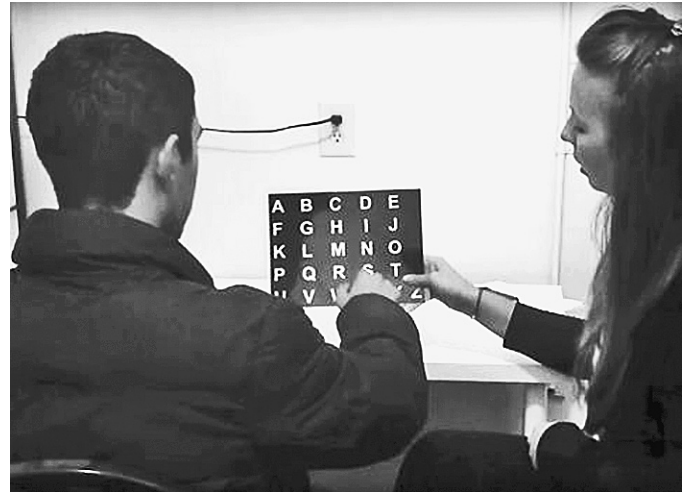
"I am each day
So always stay
Walk with me
Or let it be
Please want respect like you
Make it be true
Kind words matter to all
So all words are like a saw
That can build you tall
Or cause you to fall
Words matter to me"

Giving Voice to the Voiceless by Parisa Khosravi

Earlier this year I gave a TEDx talk on a very personal topic. It was the hardest speech I had ever had to write and present. Our intention in sharing our story was to help others, open hearts and minds, and change perceptions about autism. Here is that speech and what has happened since...I was a journalist for nearly three decades. My joy and passion in journalism was giving voice to the voiceless. The irony was that at home I had a much tougher responsibility... my kind and gentle son had no "voice."

At work, as the head of international newsgathering for CNN, I had a very different criteria for measuring my achievements, such as: meeting with Popes and Presidents, or ensuring that our teams safely reported from war zones like Syria and Iraq... even diverting a commercial airliner in order to get our people to a breaking news event. I directed the coverage of countless historic events including the earthquake in Haiti, the tsunami in Japan, the Arab Spring, and throughout the years received numerous prestigious journalism awards. 3am calls were what I was used to, and sometimes even initiated them myself in order to get an update or check on the safety and status of our journalists working in warzones and hostile environments. In fact, I cared so deeply for my colleagues' safety and well being that one of their nicknames for me was Mother Parisa.

Yet, at home, being a mother felt like the most challenging responsibility I had ever had. Maybe it is not proper to say such a thing, but it was true for me. As a first time mom, I was not sure what to expect, and kept hearing that it gets easier as they grow older. "Their sleep gets better and they start talking and you will know what they need..." This was not the case for us. My son, Payam, would be up and awake for most of the night. At around the age of two my playful and active child started disengaging. My son was diagnosed on the autism spectrum just before his third birthday. It was such an out of body experience when I heard the diagnosis. After telling us the results the doctor gave me a piece of paper with the list of three therapists for my son. It's odd how certain images stay with us. That piece of paper was carelessly copied at an angle, so the list was slanted on the page. It was such an appropriate metaphor for how different it was only about a dozen years ago. There were so few available resources, that the messy copy of a list of three specialists, was the best and only thing this top notch developmental pediatrician from a very respected medical



Payam Khosravi

center could offer me.

I didn't know what to do next, there is no road map, each child is different and results vary with each therapy. There was no time to grieve, every day counts, early intervention is key. I guess I went into a full journalist mode, and started searching for answers. We tried everything. I mean everything. I had at times 20-30 therapists and teachers come to the house every week. At the age of five, nearly two years of intense hard work and behavioral therapies went down the drain when we tried a new and somewhat unconventional method of therapy which had a completely negative impact and resulted in Payam essentially being overwhelmed by sensory stimulation. As you can imagine, this experience made me very apprehensive and cautious in trying newer methods and therapies.

At home, just as in my career, I was relentless in pursuit of answers and results. I made sure Payam was nourished with a healthy diet, exposed to continual learning and types of activities... hoping and preparing him to reach his full potential, whatever that potential may be. As the years passed, Payam attended private school and was home schooled, was exposed to travel and the news (you can imagine the news was always on in our house). He also had endless hours of educational therapies, including music, speech, occupational therapy, swimming, horseback riding, and many many more. You name it, he has done it. He is the hardest working person I know. Throughout, Payam was only able to communicate in the most basic manner with a few simple words, expressing his very basic needs—leaving us to wonder what he was feeling and thinking, and how much he actually understood from all that we were teaching him. I kept my eyes open for any new methods of communication, but also

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remained very cautious. Incidentally, a few years back, I had heard about RPM, Rapid Prompting Method, which essentially helps those who are non-verbal or non-reliable speakers to communicate by spelling out their thoughts letter by letter, on an alphabet board. As I looked into it, I got concerned about the experts' reviews that this method was not legitimate and that it was not really the kids who were spelling, but rather their teachers were moving the board and spelling for them.

I was worried about regression again, and did not pursue RPM based on what I was hearing from the experts. It's interesting how life works, this past year I happened to talk to two moms, in different parts of the country, just a few weeks apart, it was like serendipity, and they both talked about their kids' great success with RPM. Throughout all these years, I have learned that the best source of information are other parents with similar challenges, and what I was reading and hearing from many of them regarding this method was fascinating. I also attended a workshop and watched kids communicate by spelling on the alphabet board. There are stages in RPM, using different types of alphabet boards: stencil boards, laminate boards and eventually keyboards.

I made an appointment with an excellent experienced teacher in this method. She treated Payam like a typical kid, and presumed that he is fully competent. From the very first session, Payam showed us that he completely comprehended each lesson that was read to him, and started answering related questions via the letter board. I couldn't believe my own eyes. Here was my fourteen year old who had barely been able to communicate for all these years, and finally, FINALLY we were getting a glimpse inside his thoughts. But my skeptic journalist mind kept questioning the fact that he was actually spelling out the answers. I kept going back to his sessions, week after week. I had to double check, triple check, and quadruple check as he wrote on the board. I watched in disbelief as Payam understood every topic read to him, ranging from 3D printers to how the brain works to Gandhi's philosophy and the aurora lights. I observed him for eight weeks, eight sessions, talked to other moms and read an incredible book called *Ido* in *AutismLand*. At last, finally, I believed. For so many years, we had tried so many different methods and therapies, gone to each one with such high hopes, I think I was just afraid that it was too good to be true and was managing my own expectations and perceptions. PERCEPTIONS!

During my TedX Talk, I showed a clip of Payam with his teacher, so that the audience can better

visualize what it looks like. And for the purpose of making it easier for the audience to follow what he was writing, the letters he touched on the board were shown on the right side of the screen. Payam has to work so hard to control his body and eye movements as he writes. It is a serious challenge of his fine motor and gross motor skills. His teacher transcribes what he is writing, so that we can keep up with him and also have a record of each lesson afterwards. He is wise beyond his years, even if from the outside you might have a different perception. Below is Payam's full message written on the alphabet board, it took about five minutes for him to spell it out letter by letter: I WANT TO THANK EVERYONE WHO SEES THIS AND BEGINS TO SHIFT THEIR PERSPECTIVE TO HAVE MORE BELIEF IN ALL OF HUMANITY.

How many times have we been told not to judge a book by its cover? How often do we fail and completely judge others based on what we think is "normal" or acceptable? How do we know what they are thinking or feeling, if they are not able to tell us in the ways that we are used to? Why do we presume to know their cognitive levels or what they will be capable of in life? Who are we to judge?

His name, Payam, actually means "message" in Farsi, in Persian. He is my heavenly message. He has been my ultimate teacher in life. I remember, early on after his diagnosis, he was playing in the backyard, and as I was watching him it just came to me. Not, why me? Not, why my son? Instead, I thought, wow, me! Payam has chosen me to be his mom. I did not know why he had picked me, I just felt this incredible honor that I get to experience life with a very special son. I have always described Payam as walking love and my little Buddha. Not so little anymore though—he towers over me. He teaches me about patience every day and forces me to be in the present. Now through his letter board, Payam regularly writes about helping other non-speakers and wants them to know about this tool and method of communication. He wants schools and teachers to always presume competence and know that just because some students are not behaving or responding in a "typical" manner... this is not an indication of their cognitive level. He recently wrote: I THINK CHALLENGING THE VIEWERS TO FREE THEIR MINDS OF ALL PRECONCEIVED IDEAS ABOUT NON SPEAKERS IS IMPORTANT TO PERCEIVING US AS CAPABLE LEARNERS.

He cares so much about spreading this message that when I was invited to do this talk, I asked him if he wanted me to speak about it at this setting. I have deep respect for Payam's privacy and I was frankly very reluctant about sharing his story so publicly.

This is what he wrote in response to my concerns: I THINK THIS TED EVENT AND AUTISM NEED EACH OTHER. HELPING OTHERS IS MY PRIORITY. A LOT OF PEOPLE WILL LEARN FROM MY EXPERIENCE WITH LEARNING TO COMMUNICATE USING THESE TOOLS. MOM EXPRESSES HERSELF SO WELL. I TRUST SHE IS THE RIGHT PERSON FOR THE JOB.

When I pressed him on the privacy issue, he added: MY STORY NEEDS TO BE HEARD. HAPPY FOR YOU TO SHARE.

How poetic that my son gives me permission, and in the process is the one who helps me find my voice for the first time to share this emotional journey and personal quest. I did not know why he had picked me, I just felt this incredible honor that I get to experience life with a very special son.

Getting to know my son, his thoughts, aspirations, sense of humor, and a deeper insight and understanding into all the challenges which he continues to face and deal with on a daily basis, leaves me in awe of him and humbles me beyond any words I can say to you. You know that 8th lesson which finally got me to believe... it was about geysers at Yellowstone. Payam picked the lesson on geysers out of three other options. The lesson partly talked about Old Faithful and how often it erupts. His teacher then asked him some related questions, tapping into his general knowledge... she asked him "what does predictable mean?" Payam wrote: IT MEANS THAT I AM SOMEONE YOU CAN COUNT ON.

She then asked him what's predictable about you and he wrote: I AM A LOYAL FRIEND.

At the end of the lesson his teacher asked him to write about what makes him erupt?

This is what Payam wrote: CENTURIES OF DISCRIMINATION HAVE CREATED GEYSERS OF HATE AND INTOLERANCE. THESE ACTS ERUPT AND HURT THE CHILDREN OF THE WORLD NEEDLESSLY. TEACHING ACCEPTANCE IS MY LIFE'S WORK.

After seeing him write those words, both his teacher and I were in tears, Payam wiped his own tears as he finished writing this message. Later on that evening, I sat down with Payam and apologized to him for all the frustrations he must have experienced throughout the years and also my own recent skepticism. He listened to me quietly and then simply moved over and gave me a kiss on the cheek. That kind gesture told me everything I needed to hear. For all these years, his voice has been trapped in his body, and he has had to reconcile with that fact.

Finally, a window has opened up for him to

express himself and be able to share his empathy and compassion for others. He has been observing everyone and everything all along, and is now finding the power of his voice and sharing his message, his Payam with the world. He too has a deep passion for giving voice to the voiceless—regardless of the reason for their silence, be it disability, society, or self imposed. Payam uses his letter board to share the power of his voice and advocate for others.

At different points in our lives, most of us have silenced our own voice at home, at school, at work or in our communities. Why do we do that? And what is your metaphoric letter board that you can use to find the power of your voice?

When I finished the talk and walked off the stage, I wanted to know how Payam was feeling. He had watched the rehearsal the night before and of course had heard me practice a number of times prior to the big day. However, the morning of the talk when I asked Payam if he wanted to be in the auditorium while I gave the talk, he wrote on the board that he wanted to be in the room while the other speakers gave their talks and would then leave when it was my turn. I was one of the last speakers, and when my turn came up, his teacher who was with us had again checked with him if he wanted to stay or leave. Payam had changed his mind and decided to stay, and I am so thankful that he had. For him to see and experience first hand the reaction of the audience and the feeling in the room was incredibly special. I was told there was not a dry eye in the house, and Payam got to witness that himself and then felt the audience's appreciation

of his words by watching them give our talk a standing ovation. Besides the talk, our plan during our trip to Big Sky was to go and visit Yellowstone and see the geysers. On a beautiful sunny winter day we saw the park and watched Old Faithful erupt with all its might. That lesson on geysers about nine months earlier was such a turning point for us.

The talk was posted online about a month later, it was a big day for Payam and he wrote the following thoughts to his teacher: JESS I AM READY TO ENJOY THIS MOMENT OF GRATITUDE WITH YOU. RIGHT NOW I AM OVERWHELMED WITH EMOTION SINCE EVERYONE HAS BEEN ABLE TO SEE THE TED TALK AND MY STORY. THANK YOU FOR SUPPORTING ME TO DO THIS. EVERYONE DESERVES TO HAVE THE SAME OPPORTUNITIES MY GOOD FORTUNE HAS GRANTED ME. DESERVING THE WORLD SHOULD NOT BE GRANTED TO ONLY THOSE WITH RESOURCES, BUT INSTEAD TO EVERY PERSON THAT EXISTS.

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He continues to inspire me with his level of empathy and compassion and how he advocates for others at every opportunity. Payam has now advanced from the alphabet boards to typing on the key board, and has recently been asked to give a presentation at a conference at GA Tech about sensory movement differences. He has accepted and is now writing his speech on a key board. He has titled his presentation: "Rethinking Autism and Therapeutic Approaches." Payam has asked me to be his voice and read out his speech to the audience at GA Tech. But I have a bigger dream for him and other non speakers or unreliable speakers. By the way, you might wonder why I refer to them as non speaking rather than non verbal. Non verbal implies no words, they have words and the language, they just don't have speech, it is a motor challenge or as Payam calls it "a mouth that disobeys." Interestingly enough, we know and accept this challenge of a mouth that disobeys to be the case for many stroke victims.

I know technology will close the gap one day for those who have minimal speech and sounds or the unreliable speakers who can spell their thoughts. So instead of a robotic or generic computer voice reading out their words, one day their own voice can be programmed and heard via the computer. I am working with different technology companies to make this a reality. Giving voice to the voiceless was my passion and joy in journalism. My goal now is to help literally give voice to the voiceless for the non-speaking community. Or as Payam calls them the "silent champions."

I am often asked how Payam has changed since he has been able to communicate after all these years? The thing is, he has not changed, I have changed! Of course he is happy about the fact that we now know that he fully comprehends everything. However, I am the one who has shifted the most and continue to adjust. At times I still catch myself repeating a phrase or a question to him, sometimes momentarily forgetting that he understood me perfectly the first time I said it. Or I catch myself simplifying my sentences and then remember that his vocabulary and writings are stronger than mine. I have to break my own old habits and loops. It is easier said than done. What we have changed since last year is the level and variety of academic exposure. Payam's dad reads a variety of books to him every night, from the Alchemist to Positive Intelligence,

The Power of Difference to the history of Cyrus the Great in Discovering Cyrus. Payam enjoys knowing more about other individuals on the spectrum and their perspectives, he likes history and science. He has a

wonderful math teacher and he has asked her to teach him about complex theories. Payam is a brilliant chess player and solves expert level solitaire chess within a couple of seconds.

I can only imagine how bored Payam must have been for all those years as he was taught simple math or reading books way below his cognitive level. Payam now regularly writes about humanity, equality, and acceptance. Here is a recent writing by Payam: MY DREAM IS FOR THE ENTIRE WORLD TO ABOLISH THE PAIN THOSE EXPERIENCE FROM UNNECESSARY JUDGMENTS BECAUSE OF EACH PERSONS UNIQUE DIFFERENCES. PEOPLE NEED TO RECOGNIZE HOW THEIR ATTITUDES ARE NEGATIVELY IMPACTING OUR GROWTH FOR HUMANITY AS A WHOLE.

This message from my teenage son on the autism spectrum who communicates via an alphabet board and key board. A great reminder to all of us that we never know what is inside someone until we give them a chance.

Big Picture Thinking
Using Central Coherence Theory to Support
Social Skills – A Book for Students
 by Aileen Zeitz, MA, CCC
 Reviewed by Anne Carpenter

A major problem for someone with autism or Asperger Syndrome in relating to others is their difficulty in seeing "The Big Picture" or a situation as a whole. Instead, they tend to pay attention to details and can't fit the pieces of what they experience into a cohesive whole. This concept is very hard to teach, but that isn't stopping Aileen Zeitz Collucci, MA, CCC from writing a top-notch workbook for students with ASD, guiding them through this tricky process.

She begins with an introduction for parents and teachers, giving them guidance on how best to use this book. There is also an introductory chapter for the student to read. Chapter 1 introduces the student to the concept of "Big Picture Thinking." Each chapter provides a case study or example to help clarify that particular concept for the reader. In Chapter 1, it is a story called "Kids in Action." Chapter 2 delves into the different emotions, including anger, fear, envy, frustration, anxiety, envy, boredom and pride. Each section devoted to that particular feeling describes the emotion and gives examples of situations where one would feel that way, through short vignettes, then a Quick Review, describing what one's face would look like, including a photo of a person feeling anger, pride

or whatever emotion is being discussed.

Each chapter in the workbook focuses on a specific part of the Big Picture, including learning self-control, taking on the perspectives of others, communication and relationships. The text is easy to understand, yet not condescending, and there are practical ways to master each concept. For example, in the chapter on self-control, there is a list of suggestions for feeling more in control including positive self-talk, using positive affirmations, reframing thoughts (choosing the better feeling thought) and using popular slogans, such as “Just Do It” (Nike) or “Be All You Can Be” (U.S Army). The chapter also presents the wonderful concept of “rainbow thinking” – being able to think of many different possibilities and many different ways to solve a problem – as opposed to “black and white thinking” which can create problems in the social world.

Each chapter gives detailed and specific guidance in each area. There is concrete and detailed information on the best ways to foster and maintain friendships, to communicate effectively, to have sportsmanlike conduct when playing baseball or any other game, and to be thoughtful about the other person’s feelings at every turn.

Chapter 8, the final chapter, addresses “Getting the Big Picture!”, suggesting ways to help the individual with ASD see things as whole by planning, organizing and prioritizing to get the gist of what’s going on, such as that big science test next Tuesday or the school Christmas dance. There are useful tools such as a Spider Map to help track a thought by having the main idea in the center, thoughts branching out from either side, and a Describing Wheel.

With the assistance of a teacher or parent, the student can use all the chapters in the book to weave social interactions and everyday life activities into the coherent whole that they are supposed to be, instead of being caught up in minute details that detract from more effective functioning. There is even a set of appendices that include a Big Picture Thinking Checklist, an Incredible 5-Point Scale, a 5-Point Scale for managing stress levels, emotions and voice volume, a Feeling Thermometer, a “Walking in the Positive” worksheet and so much more! This is one of the best resources for children with Asperger Syndrome that I have seen. The suggestions, the concepts and the concrete tools are invaluable, and I love how down to earth this book is – no preaching, just teaching!

Thank You, Wise Jedi

by Grant Blasko

When I was asked to present at this year’s TASH Conference in Atlanta as part of the “Communication for All” panel, I was honored. As an AAC user and a freshman in high school, I knew that I would be among much more educated professional voices. Still, it was clear that my input was valued, and that felt great.

During this panel discussion, we were each asked to discuss a myth about AAC that would remind the masses of what NOT to do with a person who has communication challenges. All of the perspectives shared were rooted in the idea that we can, and should, do better by offering strategies to those of us with complex communication needs. Now, THIS was an issue close to my heart. For years, I have ranted about how professionals can easily miss the boat with people like me.

So, I chose to talk about the myth that motivation alone will lead to communication.

Living a life of silence is torturous. Your competence is questioned and misunderstood at every turn. I felt hooked to the idea that life would be forever different if I could communicate. However, I had no idea how many different skills I would need to practice to really succeed.

Rather than depend too much on the communicator’s motivation, I encourage communication partners to focus on tactics needed for success: (1) Focus on true coaching of so many separate skills, and (2) Be clear and don’t leave out the details.

I can honestly say that, prior to age 9, some of the biggest factors that affected my ability to communicate were never even addressed in my AAC training.

Imagine you are without a voice. How would you connect with others to show there was understanding between the two of you?

I start by looking for the hints of empathy in another’s eyes to give me the courage to take a risk. Even during a quick intense glance and before a meaningful word is ever exchanged I can immediately sense that there might be potential for understanding. When a communication partner follows up that split second connection with a respectful tone and thoughtful clarifying questions, and will hang in there relentlessly, I’ll happily take that path. It may be rocky, but I’ll gingerly make my way based on my gut feeling that this connection feels valuable. Maybe this is the secret sauce.

Communication is supposed to be a truly shared

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understanding between two people, not one person mimicking another person's stale ideas.

Emotionally, I need my stress level acknowledged as I am learning. Looking back, I wish I had been taught about stress as a newer communicator. When I felt my body reacting, I thought I was alone, so I would panic. Just hearing that others also experienced these reactions was so eye-opening for me. I remember feeling so out of control, and other times so tired from a pattern of failing that I could not even look at what I was supposed to do. I know now that performance is best when you are a little excited but not too anxious. I needed to hear how people move back to a calm state after the body is in Fight or Flight mode. Learning how people use self-talk was also helpful.

Physically, I needed to be told in detail how to point better, using my core body, while coordinating my eyes and my hand. These things were not intuitive to me until I had coaching and time to practice.

Cognitively, I needed to hear an intriguing story told without too many demands. Because of years of failure, at first I was afraid of any questions that put me on the spot to defend my credibility. Conversation, not testing, was needed. Easy motor responses with a nurturing reminder to slow down and think allowed me to answer and keep the conversation going back and forth. My persistence and regulation also improved because I felt success. Lowering my stress was the key. I could stay in the zone and build my stamina because I felt connected.

Some of my fellow AUTCOM members may identify with this scene. As I tell this story, I can again feel the pain I endured. Years ago, I wrote this response to one teacher's assessment:

"A good tutorial in frustration is hearing someone "crack the data" that I didn't understand -- because I didn't appear to move quickly. But I heard and understood and began the process of figuring out how to make it happen, only to hear the same command again in a sterner tone. In a flash, I am sad that I am already the bad guy with a decent effort still untapped. The shame comes quickly, and age-old misconceptions fire up my anger before too long. You may make the mistake of thinking I am angry about how hard the topic is, or that I don't like to work. The truth is I am angry at the risk I took, trying and failing, and that noting my real struggle has escaped everyone for so long. The truth is, I am frustrated about something so big inside me that the original command doesn't matter anymore. Now I don't remember the question



Grant Blasko

you asked, and you broke my heart, wielding your simple assumption, so incorrect."

Please understand that trauma may be a part of a student's past. For many of us, it can be really hard to start communication when you have been without it for so long. It might look like we don't even want it. Self-esteem may be low. Fear may be high. People may have fixed views of an individual based on prior experiences. Most importantly, we may never have seen others using AAC successfully to manage their lives. Because of these factors, it takes time for it to occur to that person that success can be possible.

It is also really hard to start communicating when the communication partner waits for you to have enough "motivation" without thinking about how else to give help when you are stuck. I had many well-meaning therapists along the way, but some mistakenly believed that everything would just come together. Guess what, I was always motivated, even when it didn't work out.

I recently saw the latest Star Wars: Episode VIII film. The wise Jedi Master Yoda coined what I thought was a great communication message for all of us. He said, "The best teacher, failure is." The moment I heard it, I related it to the "Communication for All" initiative. Yoda's quote begs for our insight into how we can always look for answers to why something isn't working. My hope is that reports of past failures will inform us to ask better questions and notice more. When there are so many without a voice waiting for our help, we owe it to them.

Thank you, Master Jedi Yoda, for your wise counsel. My special thanks also goes to Judy Bailey and Sandi McClennen for encouraging me to share here too.

There's More Than One Way to Communicate!

by Darlene Hanson, MA – CCC
REACH Santa Fe Springs, CA

All communication is valuable and informative in some way. An individual with a significant communication impairment will typically use a variety of ways to communicate on a daily basis, and it is important for each of us to recognize and encourage use of these “multiple” modes. These may or may not include speech, but can also include body language, mannerisms, emotional regulation, gestures, pointing to objects or icons on an Augmentative and Alternative Communication (AAC) system, or use of words and/or letters. One may use a certain system for a certain context, and sometimes the use of two or more modes of communication together may have its own meaning.

It is important for us as communication partners to identify, acknowledge, and respond helpfully to any and all communicative acts as they occur. It is helpful to develop a *Communication Dictionary* to document those “specific” communication acts and their meaning and to inform partners how to respond to the communication. Communication dictionaries can be shared and updated as communication skills increase or change. Of course, hands-on coaching with an individual is most helpful as well.

So what might these multi-modality systems include? First remember that body language and/or speech and states of regulation are the quickest and easiest means of communication. Typically these acts of communication can only be replaced by something that is as easy and as effective as the current “natural” system. Even when we want to “teach” a new system, we have to remember that natural communication must be acknowledged before it can be shaped into clearer and more expanded expression. It may be more effective to acknowledge a negative communication such as “I am mad” and then ask a person to use AAC to expand on the reason, rather than focus on using the “mad” icon as the goal.

Communicators and their partners should also consider various systems for the many different contexts we live in. A communicator might use an icon-based system to request his or her basic wants and needs around the house or classroom, and then use a mid-tech or high-tech system, such as the iPad with a communication application, in learning environments and conversation. What one chooses to use is going to depend on many factors, such as portability, need for visual and/or auditory output, ease in use, durability, and, of course, the baseline skill level of the communicator. One may want to use preprogrammed

communication to say “I need a drink of water please” but would want to have access to a full letterboard to create his own thoughts when needed. For example, “This water tastes funny” would more than likely not be a preprogrammed comment but may need to be said by spelling it out.

I would not recommend working to develop communication on multiple levels at once. However, as we identify the current skills and then work to expand communication opportunities, we must remember not to throw out the old ways. It is great when you see individuals manage their communication systems according to the context. My friend Neal, for example, had a very challenging time learning to communicate effectively. Now he pairs his vocalizations and approximations with gestures or sign language vocabulary to make requests, and he tells stories and engages in conversation using the preprogrammed icons in his Proloquo2Go. In addition, he types out his more expressive thoughts when he wants to provide detail to his communication. If we limited him to just one of these systems, he would not have been able to speak, via AAC, with the people of the United Nations!

Communication for each of us is a complex process. It is important for us to remember that the process is just as complex, if not more so, for those individuals with limited to no spoken communication. When we describe an individual's communication, we should be complete and describe all of the facets, strengths, weaknesses, and nuances, whether they be simple or complex. For dependent communicators, each of these pieces matters and can make or break effective communication. Let's develop communication skills and create systems and opportunities that enhance the individual's life!

If you have any comments, questions, or communication needs, you can contact REACH – Communication Services at www.reach.services. REACH has a team of speech and language professionals, assistive technology specialists, and trained communication partners to assist you. We provide assessments and therapy in the Southern California area. Training can be provided throughout the US.

This is the issue of the Communicator to share
with policy makers, service providers,
autistic people and their families and friends.

Wellspring Guild - An Introduction by Marilyn Chadwick, Board President

AutCom is an organization where advocacy is well understood if not second nature. It is a place where all approaches to communication are accepted and each person's voice is truly valued. In this article I will shine a light on something of equal value that is a true partner to advocacy – training. It is through training that people are often invited for the first time to experience alternative communication. It is through training that people are given safe opportunities to shift their thinking about people with disabilities and people who communicate through alternative means. And it is through training that communication partners develop the skills that are necessary to support a person to reach their potential as a communicator. This is not to downplay political forums and other public presentations, but part of the purpose of training is to actively confront attitudes and promote presumption of competence.

Those of you connected to AutCom are familiar with the full range of alternative means of communication. This is a place where everyone is welcome to share knowledge, hopes and dreams, and opinions. In particular, it has been a place where users of Facilitated Communication Training (FCT) have developed a voice, individually and collectively. And it is to this collective voice that I would like to introduce Wellspring Guild.

In October of 2015, we held a weekend retreat to discuss how we could more clearly forge a process of training for individuals who use AAC generally and FCT specifically. Best practice for typers and facilitators is well known, but best practice for teaching the method is not. The goal is to expand the number of trainers of FCT in this country and develop high quality training through a consistent curriculum of coursework, experience and practicum. On that weekend, we established the name and carved the mission:

Wellspring Guild: Intelligence Magnified through Facilitated Communication Training
Mission: Communication is essential to citizenship and community participation. The mission of Wellspring Guild practitioners, employing a uniformed standard of practice of Facilitated Communication Training, is to ensure for all a meaningful voice that is personal authentic, and effective.

In July, 2016, we introduced the organization to the FCT community through the Summer Institute in Columbia, MD. This organization is open to everyone who is supportive of FCT. Members include typers, family members, professionals, friends of FCT, and facilitators. Typers, families and friends can network

with each other. Organizations that use FCT also meet regularly to share ideas and problem-solve issues that involve training, implementation, and advocacy.

Facilitators are eligible to enter the training programs and develop their skills as coaches or trainers. Those interested in becoming a coach or trainer can work toward a formal status of accreditation. It is important to note that this is not certification but a process that accredits experience, knowledge and the use of best practice. In June, the Iowa 2017 Midwest Summer Institute – Inclusion and Communication for ALL – rounded out our first year as an organization. Our membership continues to grow, and we have awarded trainer accreditation to Morgan Tyner of Florida and Angie Syllas of North Carolina. A number of people have formally applied to be coaches or trainers; others have expressed interest.

This first year has focused on developing the website and the curriculum for coaches. In Iowa we provided a training for coaching and invited participants to assist the trainers in the conference sessions. We hope to continue this format. We presented at TASH last year in St. Louis and will present this year in Atlanta. We have also begun to offer webinars which cover a variety of topics through the website and which are open to all. Check us out at www.wellspringguild.org or on Facebook. There may be something that interests you.

Because of the close relationship between supporting the method as a facilitator and teaching others, we will continue to offer opportunities to learn about the various aspects of FCT. We also continue to develop the standard of best practice for teaching the method. We invite you be a part of our journey. If you are not already a member, please consider becoming a member. If you are a member as a facilitator, please consider developing your skills as a coach or trainer.



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 individual's 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.

AutCom Membership Form

Name: _____

Street Address: _____

City: _____ State: _____ Zip Code: _____

Telephone and/or fax (optional) _____

Email: _____

I want to: _____ Renew my membership _____ Become a member

I am a: _____ Person on the autism spectrum _____ Parent _____ Friend
_____ Student _____ Professional (field) _____

Enclosed is my membership fee of: _____ \$10.00 (Person on the autism spectrum)

_____ \$30.00 (Regular membership fee) _____ \$10.00 (Student membership)

_____ \$75.00 (Facilitating membership) _____ \$500.00 (Lifetime membership)

I am enclosing an additional \$ _____ to speed up the good work!

Send the above information and a check in the appropriate amount to
Anne Bakeman, AutCom Treasurer
3 Bedford Green, South Burlington, VT 05403

Autism National Committee
3 Bedford Green
South Burlington, VT 05403



Time to Renew or Join Today!

Annual membership begins in January

Membership form on page 19, and envelope included.



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 Doug McClennen, 619 N. Sheldon Rd., Plymouth, MI 48170 - or email him at: dmc@umich.edu. THE COMMUNICATOR may be copied in its entirety or individual articles reprinted without permission except when otherwise noted. Please credit them to the Autism National Committee.

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