



Volume 25, No. 1 - Spring 2019

THE COMMUNICATOR

A Publication of the Autism National Committee



Save the Date and make plans to attend!

AutCom 2019 Conference – More Power to Us: Civil Rights for Autistics

November 1-2, 2019 – Holiday Inn, Concord, NH

We are excited to announce that Grant Blasko and his mother Cindy Blasko will be presenting a keynote address. Program will include sessions by autistics and allies on advocacy, sensory/motor and emotional regulation, communication access, trauma and recovery, and more. Check our Facebook page and website for updates on speakers, sessions, and registration information. Spread the word!

Air travel info tips: The cheapest air travel deal will probably be to fly to Boston's Logan Airport and take the regularly scheduled shuttle/bus to Concord. There is no public transportation from the Manchester, NH, airport, so ground transport from there would be by rental car, cab, or Lyft / Uber.
www.autcom.org

Introduction to this Issue

We are pleased to present articles on autism and higher education, parents, and introducing and supporting communication, along with essays, poems, a song, book reviews, news, and resources. We hope that you will enjoy this issue and share it with others.

In addition, we wish to express our sincere regret and apologies for an error in the Fall 2019 Communicator in which we mistakenly published an edited version of Nick Pentzell's *Reaction to DEEJ*. It was our mistake. We have arranged, in cooperation with Mr. Pentzell, to make available the entire excellent article on our website home page — www.autcom.org.

Post-Secondary Education by Sue Rubin

Presentation at the 2018 California Lutheran University Conference:

Spectrum of Opportunity: Creating Opportunity for Access and Success in College

Hello, my name is Sue Rubin and my words will be provided by voice output technology. I would like to introduce my awesome facilitator, Renee Jackson, who will allow me to answer questions without a facilitator touching me.

I am an alum of Whittier High school graduating with a 3.98 GPA and I also scored a 1370 on the SATs. I attended Whittier College and, in the spring of 2013, earned a B.S. in History (3.59 GPA). I have won many awards and honors over the years for my work as an advocate and also served on the TASH national board of directors. I wrote and was the subject of the academy award-nominated film "Autism

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Renew Your Membership! See the form on page 15.

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is a World” and currently live independently of my parents and with the support of the supported living services agency REACH, out of Santa Fe Springs, California.

After graduating from college, with the help of Becky Tschirgi, a micro-enterprise consultant, I started my own business, Sue Rubin Consulting, to advocate for Facilitated Communication and people with autism. I feel strongly about advocating for the use of Facilitated Communication because I would not have been able to accomplish what I have without this method of communication.

From the time I was in elementary school until I began high school, I was in Special Day Classes for students with severe handicaps; however, I always had opportunities to spend some part of the day with regular education students. At the time we were assuming I was only there for social integration, since I scored what was then called “moderately mentally retarded”, with an I.Q. score of 24. We believed this because all signs of intelligence were missing. When people spoke to me their words just floated over my head without meaning. Lots of AAC low tech methods were tried, but I could never point accurately or consistently to the pictures.

When I was in the eighth grade, my educational psychologist and speech therapist introduced me to Facilitated Communication (F.C.), which trained my body and brain to work together, enabling me to access the alphabet. As I made progress with words and phrases, I began to make sense of spoken language. The nasty principal didn’t believe I could learn, so we ignored her and I continued regular classes like before, but now I was really participating in class and doing homework. An aide went to the classes with me, and my awesome mom was my facilitator at home. The regular education teachers accepted me without question.

At the end of the eighth grade we had an I.E.P. and when I was tested again using F.C. my I.Q. was 133. The principal at my neighborhood high school already told my mother he didn’t want Severely Handicapped Special Education students in his school, but the principal and



Sue Rubin

special education teachers at another high school, Whittier High, were excited about having me as a student. When I began classes, I only took three regular classes and spent the rest of the day in the special day class. The next semester I added a class and each semester added a class, until I was taking five regular classes, leaving one period for speech therapy or to meet with the educational psychologist.

Assume I was very autistic and was a mess a lot of the time. Quite often I was removed from the class and either sat in the hall and listened to the teacher, or when I was out of control I went to rest in the nurse’s office. Before I started with a new teacher, I always wrote an introduction about myself and about autism and arranging for the accommodations I would need. Each student is different and would need individualized accommodations.

As soon as my parents saw that I could read, they immediately said I should go to college. We met with a regular education counselor who told us what classes I would need to go to a University of California. We didn’t know where I

(continued on page 12)

Neurodiversity Is Our Motto!

by Meghana and Chetan Junnuru

It's April and our hearts are craving for a voice in the "April Autism Awareness Month."

Our instincts tell us it's time to consistently shift this focus to ACCEPTANCE rather than awareness. We would like to compliment people who are already on the acceptance journey. Bravo, we are thinking, because it takes an enormous effort to shift people's perspective. With such little attention on acceptance, we are not moving fast enough towards the long-term need and dreams of those with autism.

We respect those who focused on awareness; it was likely due to lack of knowledge. The majority of the focus to date has been on mundane news about the struggles associated with autism rather than the whole truth of who we are.

Society rarely saw autism as a complementing skill set. Though the abilities of people on the autism spectrum could vary allowing only some of us to participate in the community, we would love to see a shift in people's perspective toward a better future for all. Living in our bodies, we find that we can only use a minuscule portion of the limitless knowledge we have. If the community better accepts autism, it would provide better opportunities for people like us to help complement the knowledge of neurotypical people.

It has been a long struggle bringing awareness about autism. It will be an even bigger struggle getting to acceptance. That is because acceptance means that those with autism are fully included and treated similar to those without autism – in schools, in the workplace and in the community. To be very candid, we can see how big the challenge is because it calls for big training and adaptations in schools, colleges, workplaces, etc. Knowing that the recognition of autism has been on a steady rise, how are we preparing for the monumental work ahead of us?

Let us look at an example in our household. In our days of no expression, we dreamed of a day when we can share our voices. Now that we have a voice through a keyboard, we are dreaming of



Meghana and Chetan Junnuru

the day when we can mature our skills to attract a job in the community. Our fervor for such an opportunity has been increasing a great deal. The question remains if we can truly move in that direction because it is not easy to find a job with our limitations. Lowering our hopes is not an option as that would leave us in a day program for the disabled. We personally want to explore our lives beyond that and make ourselves useful to the community. We are confident that we have the strengths to do that!

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.

Invitation to Submit!

We invite autistics, friends, and allies to submit an article, poem, or news for upcoming issues.

Submission deadlines

For Summer 2019 issue – April 30

For Fall 2019 issue – July 31

My First Spa Experience by Meghana Junnuru

I joyfully picked a pedicure
for my first spa day experience
Little did I know that it involved
a most likeable massage feeling
Polar opposite experience of Molly
who hates massages

Over the years I wondered
why people got massages
But now I know
what a cool feeling it is

I planned a pedicure
on a cold day
Hot water on my 'toes and feet'
felt so good

Picked a pedicure person
that spoke nothing the entire time

She opened my sensory feelings
by scrubbing my feet
I picked a nail polish
that was most colorful
She put it on my feet
one nail at a time

Soon I was ready to go home
and show it to others
But grandma was still
getting her pedicure
We loaded ourselves
with Indian food after
Came home to lay lazy
for the rest of the day



Meghana Junnuru

Going outdoors makes
everyone feel better
It's even better
when you do it with family
I give my family a big hug
and kisses for this experience
I thank my teacher Katie
for giving me a day off

I look forward
to my next spa day
That will open
more experiences for me

I figure my next spa day
will involve a full body massage
It's my curiosity mostly
I may learn that I like it too

I will never under estimate
the power of touch
It may never be
what I think it is
Cool memories and
lovely feelings
bring joy from within

When there is a
magical experience from
outside
Lovely days are ahead
I can only anticipate in the
meantime

Two Poems by Anthony Brown A Peaceful Heart

Peace is coming so it seems
No longer lost among superficial dreams
Great feeling coming over me
Sensed oppression is relieved
Why I wonder, is it so?
Shifting energy, all aglow
In my heart I know it's true
Saving grace, is pouring through
Ascending zenith arriving now

Spreading kindness all around
Beams of light heartfelt sound
Love fuels peaceful outcomes

Peace Inside

Ready to move to a peaceful place,
Filled with love and grace,
Open meadows, starlit streams,
Joyous rapture amongst the trees,
So much beauty, touching my soul,
Feel union at my core, dearest rapture, I adore,
Healing music, natures sound.

God Will Sing You Home

Lyrics by Holly Forlenza and Megan Burt

I'll find your smile
When you're feelin' low low low down
I'll help you shine
Even when you can't find a way out
I want you to see your abilities
We've got a song to sing

(Chorus)

Raise my voice to the sky
Sing my loving on high
Love is pleasing to God
Pleasing to God
He will hear your voice too
Sing you home when you're through
Hallelujah, he'll sing you home

I can see
We got all the love we need around us
It's in the air
It's everywhere, just reach out and grab some
In every hand you hold, when eyes meet close,
serving someone in need

(Repeat Chorus)

Show somebody kindness
Show someone you care
Let somebody know that you are there

Final Chorus:

Raise our voice to the sky
Sing our loving on high
Love is pleasing to God
Pleasing to God
He will hear your voice too
Sing you home when you're through
Hallelujah, he'll sing you home
(Repeat)
Hallelujah, God will sing you home

Copyright 2014 – Megan Burt and Holly Fiscus Forlenza. Printed with permission.

Listen to the song here: <https://www.hollyspeaksup.com/store/cds/>

Megan Burt is an award-winning songwriter/performer from Denver, CO. To find out more about Megan, visit www.meganburt.com

Holly Forlenza's silence ended after 22 years. She began typing 8 years ago via supportive communication and has been determined to create a platform to teach about love. Her message of hope, possibility, and love has been shared with audiences across the country, as she encourages all people to believe in themselves. In 2012, Holly wrote a song called "God Will Sing You Home" and with support from the community, it was recorded and distributed broadly. She also wrote a book titled, "Just Because I Can't Talk Doesn't Mean I Don't Have Anything to Say." In an interview, Holly typed the following message, "We need to be more loving. Tell strangers they are beautiful. You never know that someone might have needed that to get through the day. You can change lives one friendly smile at a time. Your kindness matters; you are powerful. You can." With support from her mother, Holly is a sought-after motivational speaker and workshop presenter. You can learn more at www.HollySpeaksUp.com or follow her at www.Facebook.com/HollySpeaksUp



Holly Forlenza

Observations by Tiffany Joy Broskoskie

About Parents

When parents become best friends, it is hard to find a way to say thank you.

When parents pour their heart and soul into their daughter's happiness, it is hard to find a way to say thank you.

When parents show unconditional love and support to their daughter, it is hard to find a way to say thank you.

When parents make plans and promises and keep every one of them, it is hard to find a way to say thank you.

When parents become their daughter's most essential educators and greatest advocates, it is hard to find a way to say thank you.

When parents spend their time and money to fulfill their daughter's wants and wishes, it is hard to find a way to say thank you.

When parents immerse themselves into learning how to communicate in the only method their daughter knows how, it is hard to find a way to say thank you.

This poem is my way of saying thank you.

Thank you for the past, the present, and what has yet to come.

Thank you for teaching me to be the woman I have become.

All my love, Tiffany

The Climb

I once lived in a bubble atop the highest mountain range. No outsider able to attempt the climb so trapped inside the bubble I stayed.

Enclosed in my sphere looking down at all the townspeople gathering in conversation at the base of the massive mountain. Unable to add anything to their chatter, just collecting information inside my head. Listening to their complete vocabulary, inhaling their sentence structure, taking note of every word from my

porch in the clouds. Here I rested for quite some time becoming familiar with the sights and sounds. Now this is where the plot twists, the game changes, the light shines on me. Some adventurous soul challenged themselves to trek up the mountain and pop the bubble holding me prisoner.

Together, we began our descent down the tall, rocky range until I was on even pavement, free of anything holding me back from articulating and expressing my every thought and desire.

Freedom tasted so sweet like a juicy plum, fresh and satisfying. This chapter of my story, so sugary and delightful.

Independence so gratifying and pleasurable.

Resources on Sensory/Regulation Issues and Access

1. **Ask an Autistic** – a video series by autistic advocate Amythest Schaber
http://autism.wikia.com/wiki/Ask_An_Autistic
2. **Accessibility Resources** – Autistic Self Advocacy Network (ASAN)
<https://autisticadvocacy.org/resources/accessibility>
3. **Articles and books by Judy Endow** – autistic author, consultant, and artist
<http://www.judyendow.com/publications/>
4. **Autistic Access Needs: Notes on Accessibility** – Autistic Self Advocacy Network (ASAN) <https://autisticadvocacy.org/wp-content/uploads/2016/06/Autistic-Access-Needs-Notes-on-Accessibility.pdf>

At www.autcom.org you can read and download copies of previous newsletters as well as this current one.



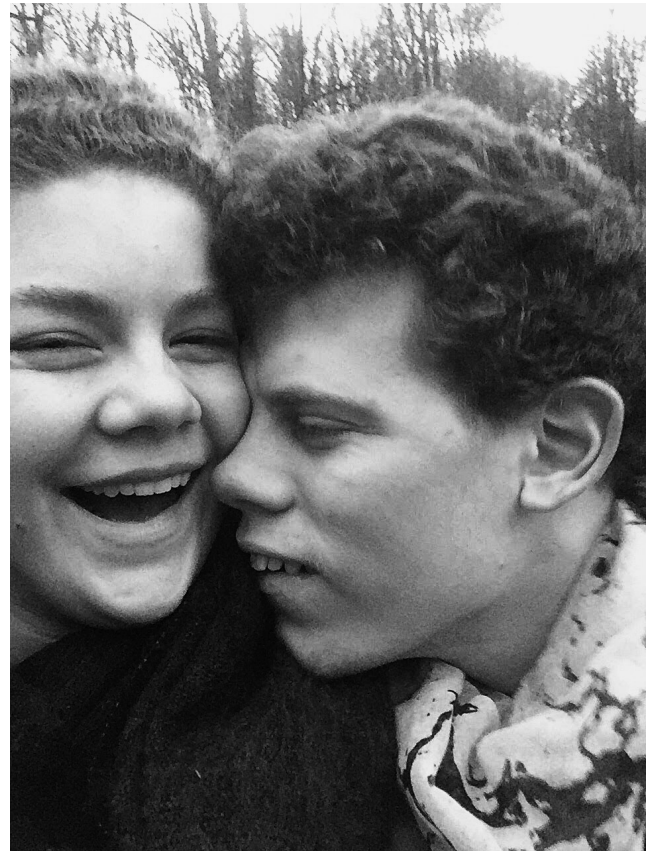
Yasmin Arshad

My name is Yasmin Arshad. I am 45 and an artist at Gateway Arts program in Brookline, MA. I recently learned to type to communicate. Until this typing started, I was depressed. No way to talk. People treated me like I was retarded. Now my life is so much better! The drapes have been pulled back, and I can be fulfilled!

As I Grew Older by Yasmin Arshad

The years that I was young
My reason was not believed.
People assumed I was dumb.
It was the drapes of negativity.
How times have changed!
Yes. Now I can type!
The drapes have been pulled back!
Let the sunshine in.

**You my want to share this newsletter
with a friend, a family member, or a
professional and encourage them to
join AutCom.**



Owen Simons & Sister Freya

Plastic by Owen Simons

Owen was supported by Wystan Simons. A few corrections were made for errors caused by involuntary movements; otherwise, it is as originally typed by the author.

i am an autistic person who loves plastic. the fact is that the plastic loves me. i actually hate playing with plastic. but i have no ability to stop my hands. i think that kind of stinks. you think you know who i am. but the fact is that that is not the real me. the real me is buried under all the behaviors. just remember that next time you see me. i believe i will overcome the obsession. i will no longer be plastic man.

About Owen:

Owen has been typing on a keyboard since July, 2018. He lives in Mitchellville, MD. He has, with his mother, been organizing a support and social group for typers called HANDS, that meets the second Sunday of each month in Mitchellville. He would love to see you there. Reach him at owensimons93@gmail.com.

New and Exciting (and Newish)

Books

1. ***The Real Experts: Readings for Parents of Autistic Children***, edited by Michelle Sutton, features writing by twelve autistic authors plus author introductions and an editorial essay by Michelle Sutton. (2015) <https://autonomouspress.myshopify.com/products/the-real-experts-readings-for-parents-of-autistic-children-edited-by-michelle-sutton>
2. ***What Every Autistic Girl Wishes Her Parents Knew***, edited by Emily Paige Ballou, Kristina Thomas, and Sharon daVanport, (2017), is a project of Autism Women's Network (2016) "Presuming competence is critical... I will grow in beautiful ways..." Features writing by 21 autistic contributors. <https://autisticgirls.com/>
3. ***Paul and His Beast*** is a novel for middle graders by autistic author and poet Sarah Stup. (2015) "Sixth-grader Paul Stephens, desperate to stay in a normal school, must tame his 'Beast'— the bizarre autistic behaviors that make other students recoil and mock." More information and free lesson plans and activities based on the book are available here: <http://www.sarahstup.com/index.htm>
4. ***Runaway Words*** by Patricia Taylor. (2019) "Addi doesn't understand why her big brother Charlie can't talk to her. When her mom tells her that Charlie lost his words, Addi, with some help from her younger brother, embarks on a mission to find them... In the end, she discovers there is more to communication than just words and more than one way to say 'I love you.'" <https://www.amazon.com/Runaway-Words-Patricia-Taylor/dp/1543955177>
5. ***Life in Letters: A Book about Autism*** by Lia Assimakopoulos. (2019) "Hear the unheard voices that resonate with magnitude. *Life in Letters* tells the stories of young, nonspeaking individuals living with autism... Using the experiences of...nonspeakers, she debates

some of autism's most misunderstood yet important aspects, allowing the voices of each individual to shine through her writing.

<https://www.amazon.com/dp/1983230162>

Articles

"Augmentative and Alternative Communication for Speaking Autistic Adults: Overview and Recommendations" by Alyssa Hillary Zisk and Elizabeth Dalton in *Autism in Adulthood* (2019). "In this article, we provide an overview of the speech differences autistic adults choose to support through AAC, including varying difficulties with speech depending on environment and content. We also discuss the technologies and strategies adopted by autistic adults, . . . barriers to AAC use, . . . and the cost of dedicated AAC applications or devices. We then provide suggestions for autistic adults, people supporting autistic adults, and researchers. Overall communication—rather than speech—should be prioritized."

<https://doi.org/10.1089/aut.2018.0007>

Videos

1. Moving Mouths, a video poem by Heathar Barrett in the UK <https://www.youtube.com/watch?v=Ri6hzTDOMEc>
2. Julia Bascom Speech at ASAN Gala 2018 – <https://www.youtube.com/watch?v=OmYtwBfesHM>

Blogs

1. BEINGAUTISTIC: An Interview with Emma Van der Klift <https://www.broadreachtraining.com/being-autistic-an-interview-with-emma-van-der-klift/>
2. WeAre Like Your Child – "WALYC is a group blog dedicated to countering the misunderstanding that autism/disability acceptance means pretending that our struggles and challenges aren't real or significant. This is where we talk about what our real challenges are, and how we strategize, problem solve, adapt, and work with them to build satisfying, sustainable lives as disabled people." <http://wearelikeyourchild.blogspot.com/>

Autism and Everyday Executive Function

by Paula Moraine - Review by Anne Carpenter
Jessica Kingsley Publishers, 2016

As more and more is understood about the autism spectrum, there has been more interest in how this condition affects Executive Functioning or EF — that complex constellation of brain functions that includes planning, impulse control, organization, memory, attention and flexibility, and how to deal with situations when something goes horribly wrong. This has been seen as an area of weakness in people with autism, but it is not well understood. This book is a fascinating and refreshing look at EF from the point of view of a Finnish woman, Pia, who is autistic.

From the get-go, I found this book amazing, because in the introduction Pia states that we need to teach EF skills before teaching social skills, which makes so much sense to me. After all, the child with ASD needs to learn to think before telling the teacher that her green and purple plaid dress is hideously ugly! This would set the stage for a newer, possibly more logical approach to helping folks with ASD navigate the social world. The author covers different areas that can relate to EF, including sensory integration, language and communication, and helping the person use EF through Autism Access Points—relationships, strengths and weaknesses, review, preview and mental image, self-advocacy, rhythm and routine, motivation and incentive, and whole-to-parts and parts-to-whole. Each of these is described in a chapter along with how each is used to help the student develop better EF skills.

In addition, the author describes EF as experienced by the autistic person himself and how that differs from “typically” developing people, so that teachers and parents can understand where that person is coming from if his thinking or logic seems “off.” Each chapter includes case studies to clarify the concepts, and at the end, we are treated to Pia’s unique ideas coming from her experiences on the autism spectrum. I was struck by her new and original ideas, such as encouraging people with ASD to relate to the so-called “neurotypical” world, rather than just learning to adjust to it, as has been the traditional view. This allows the individual to learn at his or her own pace and to

relate to the world in newer and more unique ways, that could possibly move society forward.

I was prepared to write off this book as being muddled and confusing, but I discovered that one needs to read the material several times, as it is multilayered with concepts that may be unfamiliar to most readers. And Pia’s description of her experience with ASD is yet another portal into understanding how executive functioning may, indeed, work differently on the autism spectrum. If the reader feels a little lost on this new Yellow Brick Road, there’s always the Executive Function Map in Chapter 6, including examples, that is a way to break down the various aspects of EF, such as Organization, by different areas such as Accommodations, Approaches, Strengths, Weaknesses, and Learning Goals, so that the student has specific and targeted areas to work on. In many ways, this is an amazing book and a must-have for all parents and teachers of kids with ASD.

Save the Dates

Autospace 2019 – Conference of the Association for Autistic Community (AFAC), Thursday afternoon August 15, 2019, through Monday morning August 19, 2019, at the Tamarack-Butzel Retreat Center, Ortonville, MI.
<https://sites.google.com/site/autospace2019/>

Inclusion Connection – Two-day Augmentative and Alternative Communication Event – June 19-20, 2019, Candeo Church in Cedar Falls, Iowa
<https://www.communication4all.org/>

Inclusion Works Summit – Friday, June 21, 2019, Hawkeye Community College, Waterloo, Iowa
<https://www.inclusionworkssummit.org/>

Motormorphosis – Nonspeaking Community Consortium Conference – July 27-28, 2019, Executive Conference and Training Center, 22685 Holiday Park D, Sterling, VA 20166
<http://nonspeakingcommunity.org/>

I Have been Waiting All My Life to Do This

by Marilyn Chadwick, M.A., S/LP (Speech/Language Pathologist)

I have done many assessments over the years to determine the benefit of supported typing for an individual, but as I contemplate the idea of 'readiness,' one assessment stands out. She was eleven, with a slender frame and long black hair. She was nonverbal. Her caregiver wasn't sure she would sit long enough for the assessment. But sit she did and respond she did. When given the opportunity to express her own ideas, she exclaimed, "I have been waiting all my life to do this." She was young, but the tone of her words implied 'forever.' On the outside, she did not look ready. On the inside, she was ready.

Why is that? Why does the outside present such a different story than the inside for an individual? Most of us experience from time to time incidences where we feel we are misunderstood or our true nature is misrepresented. We either walk away or work to repair the discrepancy. 'That's not what I mean.' 'That's not who I am.' But in that experience we retain our sense of self, and if we are lucky we get others to agree with that sense of self. For the nonverbal community, for those who type to communicate, the sense of self is often sacrificed and the outside view prevails. The inside view remains hidden. For them, the stakes are higher.

Let me explain with another story. I first met this boy when he was ten and continued to see him regularly over the next few years. Many sessions would take 20-30 minutes just to settle him. Invariably we ended up in the corner with him sitting on my corner end table, complete with pillows and covered with a sheet or blanket. Even after considerable effort to settle, I knew that in any moment, he could bolt. During one of our conversations, he talked about school and his teachers. "I want them to see the boy." We had a strong relationship, so I took him to task, saying "the boy has to show up." His response was, "that's hard." Months later his mom shared that he had had a particularly bad day at school; his behavior was awful. I turned to him and asked him, "did you leave the boy home?" He admitted, "no, the boy thought it up and the autism carried it off." He was fully aware of the discrepancy between his

inner world and his outer world, but his resources could only lead him down the path that confirmed for others that their perceptions of him (the very thing that made him angry) were correct. He knew the stakes, but he couldn't handle the stakes.

Overwhelming sensory sensations, flooding emotions, distracting elements in the environment add to a general need to figure out how to get a message out, either independently or with support. They can be causative or unrelated to the moment. They impact the entire learning process of using typing to communicate, making getting started difficult and working toward independence near impossible. Especially in the early stages of typing to communicate, practice sessions can be fraught with interruption as communicators struggle with the emotional impact of having the opportunity to express their thoughts.

Supporting communication means recognizing the emotional and sensory elements that interplay with the process. It means taking care of the environment in order to minimize the impact of sensory overload. It means checking our emotions at the door so that they do not negatively affect the communicator's efforts to communicate. It means picking up on the 'first signs' from the communicator that indicate the shift toward overload. It means building a channel of communication with the communicator that problem solves those moments. It means developing a dialogue that fosters solutions that the communicator can manage on their own. In short, we cannot be effective supporters of those who type to communicate without also being good problem solvers with respect to their sensory and emotional needs.

Solutions are needed for both short term situations and long term gains. An example is useful here. One woman I have worked with had great difficulty in entering new situations. She did not want to go outdoors. When she was outdoors, her walk was slow and tentative. She could not go out without a cap as she was light sensitive. Transition from place to place was quite difficult as she resisted getting out of the car. Her ability

to type was also tied to specific situations and specific people. Her mother was the first to note the constant dilation of her eyes, a sign of anxiety. So the short term use of the cap was good, but the impact of her emotions was still quite limiting.

Long term solutions were met through diet, reflex exercises and workouts at the gym. She now easily goes outside. She walks, runs, jumps and climbs. But the challenge of transition is not over. Along the way, she had developed her own way of dealing with her anxiety and that was through the use of a very loud voice. The general emotional overload is gone, but the solution she

created is not. It is a challenge that she is currently tackling as she communicates her experience through typing. What initially looked like a sensory sensitivity was really more a part of her overall emotional profile. We had to solve the one in order to solve the other.

Each person is different in how the sensory processing, emotional regulation and motor planning interplay with each other. The solutions, both short term and long term also need to be tailored to each person. Dialogue with the communicator is very valuable in creating solutions that will truly meet the person's needs.

Thumbs Up & Thumbs Down

Thumbs Up to the Inter-American Commission on Human Rights (IACHR) for issuing Resolution 86/2018 Precautionary Measure 1357-18, December 3, 2018, requesting that the United States "adopt the necessary measures to protect the rights to life and personal integrity of all persons with disabilities who reside at the Judge Rotenberg Educational Center; particularly by ensuring that the Center immediately ceases the use of any aversive measure, including the electro-convulsive therapies...." The entire document is available here:

<https://www.documentcloud.org/documents/5632074-Resolution-86-2018-PM-1357-18-US.html>

Thumbs Up to Vermont's Department of Department of Disability, Aging and Independent Living for its recently published statement reaffirming its commitment to supporting communication choice and the use of facilitated communication:

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

Thumbs Up to CCACaptioning for its ongoing advocacy and reporting on progress for universal real-time captioning for all, including at museums, airports, speeches (Captions Capture Votes), emergency notifications--everywhere. Captioning helps with access to information, language and literacy learning, and more.

www.ccacaptioning.org and **CCAC Captioning** on Facebook.

Thumbs Down to the AAIDD (American Association on Intellectual and Developmental Disability, formerly AAMR) for adopting a new position in January 2019 against the use of Facilitated Communication Training and Rapid Prompting Method, thereby rejecting the voices and advice of many individuals with limited communication who have found these methods helpful in their communication journeys.

Thumbs Down on the CHOICE (Creating Hope and Opportunity for Individuals and Communities through Education) Act, introduced by Senator Tim Scott on January 16, 2019, which relieves participating schools from requirements of IDEA and from accountability under the Every Student Succeeds Act.

Remember to save November 1-2 for our 2019 conference and encourage friends, family, and professionals to save the dates as well.

**AutCom 2019 Conference:
More Power to Us –
Civil Rights for Autistics**

(Sue Rubin – continued from Page 2)

would be going to college, but the requirements for the UC system would be enough for wherever I decided to go. That determined some of the accommodations that I needed. Since I was taking college prep awesome classes, we were asked whether we wanted changes to the curriculum. I insisted that I should really earn a regular diploma and do the same work as everyone else. The only accommodations I asked for were extra time and a special place to take tests. I was told I could have extra time for homework assignments, but that was not a good idea, because once you get behind, it is difficult to catch up.

We tricked the school district with one accommodation. I couldn't use the microscope in biology class because I couldn't close one eye and see anything, but since I was not labeled as multi-handicapped I was not entitled to special equipment. There was a student who came to school so drugged that she sat in a wheel chair all day and didn't do anything, but she qualified for special equipment, so she was enrolled in my biology class, and we got a microscope that worked with a projector so I could look at a screen. Actually, it was very beneficial for the whole class.

I also needed an accommodation in the dance class. Can you picture me dancing when I can barely walk without falling? The girls in my class decided that they would choreograph a dance that required me to stay in one place. I was in the center and they were in a circle dancing toward me and away from me. I also chose the music. The girls also included me when we rehearsed after school at home.

I also had an accommodation that was actually made to help staff. The staff ratio was usually 3 to 1 which worked fine for me in non-academic classes, but I needed my own facilitator in college prep classes. We tried 2 to 1, but the regular education teachers complained. Really awesome special education teachers split up the special ed students, so we always were on a teacher's case load, but for support in the class, the awesome teachers, without big egos, did the same work as instructional aides. Even with this arrangement we didn't have enough staff. The problem was solved by the special education

teacher asking the regular ed teacher if a student could be my facilitator. He agreed as long as it didn't affect the student's work and the special ed teacher was my facilitator for tests. Actually, several students volunteered. A really quite awesome student was chosen just because he was in my honor's English class and could walk me there. The accommodation was that when there were lots of problems on a work sheet, we would each do half. He often came to my house to do homework and we typed together about other things. He said I really helped him with writing and spelling. He protected me from bullies when we walked to class. Because he was class President and on the football team, students respected him when he yelled at them and said I was smarter than them. Actually, he came from a very different background from me. His family always moved every year, and when we picked him up we saw they had no books in his house. We both got A's.

He was only one of the peer tutors I had. I loved not having an instructional aide or teacher with me in class. Peer tutors became friends when we were not in class. My best friend when I was a freshman in high school went to work for me after we graduated and supported me in college. I was a bride's maid in her wedding, and we are still friends.

The reason I was able to attend college really was because of the awesome high school I attended, the really awesome regular ed and special ed teachers, the awesome regular ed students, and my awesome mom who worked with me on homework at least three hours every night and on weekends. I had mentioned being in Honors English in the ninth grade, which is amazing since I was in a Special Day Class in the eighth grade. The only reason I was there was that the other English classes used cooperative learning and sat around in a circle. This was awful for me because I couldn't stand looking at everyone's face. Please be assured when I was in college I was O.K with it. I was put in Honor's English because it was taught as a lecture class. Actually, this was an accommodation made by changing the environment. No one expected me to be able

to do the work, but this was really perfect for me. The teacher was very well organized and the curriculum was very structured, so I got an "A".

All the teachers with a couple of exceptions were great and enjoyed having me as a student. We were afraid of what would happen when I had to take geometry from a teacher who was going to retire after that school year. The special ed teacher spoke to him about me, and he said it was his last year of teaching and wouldn't make any accommodations. Fortunately, I didn't need any, and when he spoke to my parents at Back to School Night, he said he knew I understood the material by my descriptions of angles. He also said when I looked at him he knew I was looking into his soul. I actually looked at his eyes and saw sadness.

I had another English teacher who believed in Facilitated Communication, even though I needed someone touching my arm, because she recognized the same writing style with several different facilitators. She knew the facilitator wasn't moving my hand. She also believed I was a good writer and asked my mom if she could work with me after school. When I took physics, I had to write up a lab for homework but couldn't remember anything about it, so I created a lab that I thought would demonstrate what we had been studying. The teacher asked my parents to come to a meeting. When I was asked why I did that, I said I thought my idea was better than his. He agreed and said he would use that in the future. I got an "A" in physics.

The only awful experience I had with a teacher refusing to make an accommodation was for Spanish 3. Since we live in a very Hispanic area and my high school was 73% Hispanic, I was the only non-Spanish speaking person in the class, which really had nothing to do with the accommodation I needed. One of our first assignments was to make a collage with pictures and text in Spanish. I chose the pictures and my mom pasted them on a big piece of poster paper. I wrote the text. The teacher gave me an "A" on that and an "F" on oral presentation. My mom first talked to the teacher who said I had to speak Spanish to get a grade. My mom said if I lived in

a Spanish speaking country, this is how I would communicate. She refused to budge, so my mom contacted the chair of the Special Education Department and the principal. We didn't want to take legal action because until then everyone had been so great. Before the meeting my mother contacted the teacher I had had for Spanish 1 and 2 and asked if he would teach me Spanish 3. He agreed so we met with him after school on Fridays. He only asked that the principal say he was being forced to do it. He said, "I have to live with these people." We really enjoyed our classes and again I got an "A".

As wonderful as my high school experience was, I was often frustrated by the staffing. Instructional aides were young and inexperienced and came with no knowledge or training in Facilitated Communication. Except when a Special Ed teacher was supporting me, I was unable to participate in class. Some peer tutors were good facilitators. When I was a freshman, a new instructional aide came to English class with me and just sat there. A classmate said, "Don't you know how Sue communicates?" and sat next to me so I could use F.C. to participate. The aides were eventually trained in F.C., but usually didn't come back the next year.

In spite of the few problems I had, we were correct in thinking I could go to college. My grades were excellent. The awful S.A.T. would be the only thing that would stop me. My mom contacted several colleges in the area and asked about having it waived. None would do that. Once again, the awesome high school staff came to my rescue. The summer before I graduated the educational psychologist and a special education teacher volunteered to prepare me for the S.A.T. and be facilitators when I took it. All summer they came to my house and I took practice tests. We knew I had to be completely comfortable with the format and only pay attention to the questions. People were worried that the testing company would be against me using Facilitated Communication, but when we asked for an accommodation for extra time, the school counselor told them I would be

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using Facilitated Communication. They contacted the educational psychologist and asked her how that would work. By that time, I was typing independently with my mother and a peer tutor, but needed an occasional tap on my shoulder with other facilitators. The psychologist told them she would only be keeping me focused. We also sadly used Pringle's potato chips and took three days to do it. We also knew I had to be in a familiar place, so we used the high school conference room where I had been taking tests.

We also knew that if the facilitator interrupted my attention by filling in the answers, we would have to start over again in getting me to pay attention, so we had another person in the room whose only job was to fill in bubbles. That way we did not interrupt my rhythm. The educational psychologist was my facilitator for the English section, and my Special Education teacher was my facilitator for the math section. We spent a lot of time figuring out how to do the math section with Facilitated Communication. When I took math classes, I was able to work hand-over-hand, but we didn't want to do this for the S.A.T. My father, who is a mathematician, and my special education teacher devised math boards. These were my choices of how I would attack the problem and solve it.

This was long ago, so I didn't have to write an essay. I scored 1370, which at the time was very good.

We began looking at colleges in my senior year. My parents made appointments with a few Directors of Disability Services. The results were quite different. At one small college the Director said she thought I wouldn't be treated well and discouraged me from applying. At Cal State the Office of Disability Services was fine, but when I visited the campus I knew I couldn't handle the huge crowds or arrive on time for my classes. We considered Claremont College but decided it was too far away. When my parents met with the Admissions Department at Whittier College, they strongly suggested that I should apply there. They were impressed with my GPA, which was 3.98, since I had taken some honors and A.P. classes, and were impressed with my teachers' recommendations. We also took a walk on

campus where almost all the students we passed smiled at us. At the time Whittier College had about sixteen hundred students and all the support services I would need except a facilitator. We had to find an adult agency that believed in Facilitated Communication, so the choice was WAPADH, now called REACH. I also wanted to go into Supported Living when I started college, and WAPADH could do that too. We started having WAPADH staff come to my house for homework with me when I was in my senior year, so I would be comfortable with them when I started college.

We liked Whittier College because of the small classes, the location, and we already knew a lot of faculty members because my dad had taught there when I was younger. I was accepted with a \$38,000 academic scholarship even though they knew I would always be a part-time student. They said they knew I would be part-time not by choice, but because of my disability.

It took me sixteen years, but I graduated in 2013 with a Bachelor's Degree in Latin American History. My college career actually was wonderful, and perhaps in the future we will meet again and I can tell you about it. I hope this presentation helps you in your pursuit of a post-secondary education.

I love being self-employed because it allows me flexibility. In spite of my accomplishments, I often have days when I am so awash in autism I can't function. When I have to prepare a presentation, I can start well in advance, so I am prepared by the time of the event. When I have meetings using GoToMeeting or Skype, awesome staff are able to get me into working mode. I am now working under a grant with Autism Speaks which allows me to consult with no charge to the person with autism and his/her family.

Thank you.

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Principles of the Autism National Committee

As a member of the Autism National Committee I endorse for all people with autism spectrum differences, 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.

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