



# THE COMMUNICATOR

*A Publication of the Autism National Committee*



## **More Power to Us - Civil Rights for Autistics**

**You don't want to miss this outstanding conference**

**November 1-2, 2019**

**Holiday Inn Conference Center Concord, New Hampshire**

### **Keynotes**

#### **Friday**

- Nancy Weiss, Shain Neumeier, and by video, Jennifer Msumba: What will it take to end mistreatment at the Judge Rotenberg Center?
- Amy Laurent and JâcquÛelyn Fede: What's level got to do with it? Understanding and supporting emotional regulation

#### **Saturday**

- David James ("DJ") Savarese – Artful Activism: Why the how of what we do matters
- Grant Blasko and Michael McSheehan - Give the kids a break! For students with complex communication needs, Universal Design for Learning provides stress relief AND equitable access to education

### **Breakout sessions and presenters**

- Nancy Weiss and Shain Neumeier: Follow up session - What IS helpful to support people who have significantly challenging behaviors
- Tauna Szymanski: Introducing CommunicationFIRST: The first national civil rights organization for America's 5 million nonspeakers
- Bridget Liang and Noah Adams: Trans and autistic: A whole world of possibilities
- Estee Klar and Adam Wolfond: Neurodiversity in relation: an artistic intraethnographic practice
- Zach Rossetti, Lisa Keller and a panel of autistics: Friendship
- Catherine Boyle: Thinking about housing
- Rob Cutler and Thalia Vitikos: Gaining control of your Life after PTSD
- Shannon Desilets: PTSD and treatment using MNRI
- Panel of autistic AAC users: Everyone has the right to communicate
- Tauna Szymanski: How to get communication access at school

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**Renew Your Membership! See the form on page 7**

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(Conference information continued)

### **More Breakout Sessions & Presenters**

- Christine King, OT: Interactive session on sensory issues
- Topics of other sessions include postsecondary issues (education and employment), methods for communication access, and more!
- Additional presenters include Sue Rubin, Jenn Seybert, Kris Medina, Mark Utter, Matt Hayes, and others.

### **We hope you can join us!**

Make your hotel registration. Rooms are going fast. 603 224-9534

If you are flying, going to Boston Logan Airport, then taking the bus to Concord is the least expensive way. Check the bus schedule at

<https://concordcoachlines.com/route/concord-to-boston-logan-airport/>

and make your airline reservation accordingly.

(Uber or Lyft from Manchester, NH, is about \$120.)

See [www.autcom.org](http://www.autcom.org) for more information.

To register online, go to

<https://www.eventbrite.com/e/autcom-2019-conference-more-power-to-us-civil-rights-for-autistics-tickets-66452004735>

A registration form is also included on page 5 of this newsletter  
and can be downloaded from our website.

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## **Autistic Filmmaker Mark Utter on AutCom 2015**

Following our 2015 conference, one of the presenters, Mark Utter, wrote a blogpost about his experience. He has given us permission to reprint that post from [www.utterenergy.org/blog/](http://www.utterenergy.org/blog/)

### **Reaching Up Through Key and Letter Boards to a Brighter Life October 23, 2015**

Dear Beloved Blog Readers,

Good autumn wonders are all around us. You must be thinking I forgot you since it has been a while.

I am going to tell you a bit about my trip to the AutCom conference I attended last month in Manchester, New Hampshire. I so enjoyed hanging out with other autistic minded folks. I was excited about the address I gave my workshop participants. They asked me great questions about my gaining experience typing.

Here are my answers for some:

Q- When did you start using FC?

M- It was not really so much a start as much as a very slow rolling ball started down the path to communication.

Q- How did your life change when you created your movie?

M- I was outed as an intelligent man.

Q- I can imagine it was nerve wracking to share your artistic work with others. Did you have to overcome some anxiety about doing that?

M- I was so needing this change and the whole long many-year process bringing the movie to life very much rose over any artistic anxiety.

Q- Do you feel like you have like-minded friends and when did you get them?

M- Oh what a smart wise question, Graciela, I don't think I had like-minded friends when I was your age but through my movie I gained my first friends both autistic and not.

Oh, Graciela is a fine thinker and shares the big communication impasse I do. We can't share the thoughts rolling through our big minds with our voices. We need access to typing and methods that control our focus so we can select the letters we want and build logical, beautiful sentences. I am pleased to let you know that Graciela has joyfully stepped into the limelight with her blog, [www.daretolisten.org](http://www.daretolisten.org). Love for you to check it out and convince her to write more.

I want to thank you for having fortunate moments to check out lost minds yearning for connection. Hope to be in touch soon with more happy reports.

**Donate to support autistics to attend the conference.**

An envelope is enclosed. You may want to renew your membership for 2020 at the same time. The membership form is in this newsletter.

If you can't attend the conference without scholarship help, contact Anne Bakeman at:  
[anne.bakeman@hotmail.com](mailto:anne.bakeman@hotmail.com)

## **From the Editors – As AutCom enters its 30<sup>th</sup> year . . .**

It is good to look back on our beginning to see how far we have come and to recognize how far we still have to go. Our founders were a small group of innovators--parents and professionals dedicated to seeking social justice for autistic people and others with similar challenges. They were frustrated that no organization at that time would take a stand against the use of aversives, including the use of electric shock, nor work actively to end their use, so they formed Autism National Committee – AutCom - the first autism advocacy organization dedicated to “Social Justice for All Citizens with Autism” through a shared vision and a commitment to positive approaches.

From its founding in 1990, AutCom had a clear vision of a better world. We took a strong stand against the use of aversives and urged the use, development, and promotion of positive, respectful approaches for every aspect of life. AutCom called for high quality community services for all autistics and people with related disabilities in education, residence, jobs, and job training and support services for individuals and families. We focused on disseminating available new information and knowledge of autism that would lead to support and understanding.

Very quickly, autistics became an equal part of that partnership, taking positions as board members and officers for equal standing among autistics, parents, and professionals. Our conferences, publications, and activities are focused on promoting autistic voices, rights, and social justice. As in all our conferences, this year's keynote presentations and breakout sessions include a majority of autistic presenters, co-presenters, and panelists.

## Thumbs Up & Thumbs Down

### Thumbs Up

**Thumbs Up** to TASH for elevating Communication Access to the status of National Agenda Community of Practice: "Promoting access to communication strategies as a human right for non-speaking individuals across the lifespan."

<https://tash.org/about/communitiesofpractice/>

**Thumbs Up** to the United Nations for this year's UN Autism Awareness Day Assistive Technology Interactive Sessions, featuring autistics.

<http://webtv.un.org/meetings-events/watch/2019-world-autism-awareness-day-observance-theme-assistive-technologies-active-participation/6021777181001/?term=>

### Thumbs Down

**Thumbs Down** to Sesame Street and Sesame Workshop for using its autistic character Julia to promote Autism Speaks' 100 Days Kit and Screening Tool in a new ad campaign. This move led Autistic Self-Advocacy Network (ASAN) to end their partnership with Sesame Street/Sesame Workshop (<https://autisticadvocacy.org/2019/08/asan-has-ended-partnership-with-sesame-street/>).

The Autcom Board wrote a letter to express support for ASAN and to detail our concerns. We applaud emphasizing the importance of early diagnosis and provision of education and other resources. However, we do not support harmful perspectives in the Autism Speaks documents that liken autism to cancer, compare having an autistic child to losing a child to death, and assume that if a child does not demonstrate clear understanding of something or display observable interest in others, that there is indeed no understanding nor interest.

***"You should not have to be charming to get the help you need."***

Herb Lovett, 1996

## New and Exciting Books

*Talk to me: What educators (and others) can learn about de-escalation from hostage negotiators* by Emma Van Der Klift, August, 2019

*Back from the brink: Stories of resilience, reconciliation and reconnection; the hero's journey through the minefield of autism* by Tim Chan and Sarah Chan, 2019

*Communication alternatives in autism: Perspectives on typing and spelling approaches for the nonspeaking* by Edlyn Vallejo Peña (editor), September, 2019

*The Elements* (a collaborative discussion of themes) by Tito Rajarshi Mukhopadhyay and Sarah Sohn. 2019



### Frozen by Yasmin Arshad

Today I built a snow girl.  
Frozen just like me.  
No name is for her sorrow.  
She is waiting for spring  
To thaw the autism ice,  
But is there any spring for me?

**MORE POWER TO US: CIVIL RIGHTS FOR AUTISTICS**

November 1-2, 2019 Holiday Inn Conference Center, Concord, NH

**Make your hotel reservation. Call (603) 224-9534 and mention AutCom Conference for reduced rate. All registrations include breakfast and lunch with options for gluten-free, casein-free and vegetarian.**

**Entire Conference**

Autistics; support person for autistic attendee (limit one at this price); students  
 Number of participants \_\_\_\_\_ x \$150 = \$ \_\_\_\_\_  
 Family; friends; others  
 Number of participants \_\_\_\_\_ x \$190 = \$ \_\_\_\_\_

**Friday only**

Autistics; support person for autistic attendee (limit one at this price); students  
 Number of participants \_\_\_\_\_ x \$110 = \$ \_\_\_\_\_  
 Family; friends; others  
 Number of participants \_\_\_\_\_ x \$150 = \$ \_\_\_\_\_

**Saturday only**

Autistics; support person for autistic attendee (limit one at this price); students  
 Number of participants \_\_\_\_\_ x \$110 = \$ \_\_\_\_\_  
 Family; friends; others  
 Number of participants \_\_\_\_\_ x \$150 = \$ \_\_\_\_\_

**DONATION TO SUPPORT THE ATTENDANCE OF AUTISTICS \$ \_\_\_\_\_**

**Total (Registration and Donation) \$ \_\_\_\_\_**

Cancellations before October 20 less 10%. No refunds after that date, but you may transfer your registration to another person at the same or lower cost (or higher cost by paying the difference).

Participant name/names: \_\_\_\_\_

Address: \_\_\_\_\_ City: \_\_\_\_\_

State: \_\_\_\_\_ Zip: \_\_\_\_\_ Phone: \_\_\_\_\_

E-Mail address for confirmation: \_\_\_\_\_

**Select method of payment. Submit using mail-in and fax instructions below.**

\_\_\_ Check (make payable to **Autism National Committee**)    \_\_\_ Purchase Order (enclose copy of purchase order)

Visa/MasterCard/Discover #: \_\_\_/\_\_\_/\_\_\_/\_\_\_ - \_\_\_/\_\_\_/\_\_\_ - \_\_\_/\_\_\_/\_\_\_ - \_\_\_/\_\_\_/\_\_\_ Exp. Date: \_\_\_/\_\_\_

\_\_\_\_\_  
**Name on card** (please print)

\_\_\_\_\_  
**Signature**

Mail or fax payment and registration form to  
**Autism National Committee**  
**Anne Bakeman**  
**3 Bedford Green**  
**South Burlington, VT 05403**  
**Phone: 802 658-3374    Fax: 802 658-8061**

**Indicate food allergy needs here.**

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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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### AutCom Annual Membership Form

Join any time. Renew each January (except for Lifetime Members).

Name \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zipcode \_\_\_\_\_ Phone \_\_\_\_\_

Email \_\_\_\_\_ Newsletter by email \_\_\_ or print \_\_\_

I want to \_\_\_ Renew my membership \_\_\_ Become a member

I am a/an \_\_\_ Autistic person \_\_\_ Family member \_\_\_ Friend

\_\_\_ Student \_\_\_ Professional (field) \_\_\_\_\_

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

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

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

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

As a donor, I want to be listed \_\_\_ by name \_\_\_ anonymously.

Send this form or a copy and a check payable to Autism National Committee 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 7



THE COMMUNICATOR is a publication of the Autism National Committee, Inc., a 501 (c) (3) charitable organization founded in 1990 to protect and advance the civil rights of people with Autism/Pervasive Developmental Disorder and related disorders of communication and behavior. Contributions of articles, information and letters are welcomed. The Communicator does not carry advertising or fund raising announcements, and we reserve the right to edit all submissions. Your comments are actively sought. Send them to [communicator@autcom.org](mailto:communicator@autcom.org)

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### **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](mailto:bccutler@aol.com), to request additional copies. Be sure to include your mailing address.

### **AutCom Officers**

Lisa Keller, President  
Anne Carpenter, Vice-President  
Judy Bailey, Secretary  
Anne Bakeman, Treasurer  
Sandra McClennen, Past-President

### **The Communicator Committee**

Co-Editors, Judy Bailey and Sandra McClennen  
Doug McClennen  
Barbara Cutler, Ed.D.  
Rob Cutler