



# THE COMMUNICATOR

*A Publication of the Autism National Committee*



## Restraint/Seclusion Bill In Senate “Keeping All Students Safe Act”

by Jessica Butler

Senator Tom Harkin (Chair, Health, Education, Labor and Pension Committee) introduced S. 2020, the Keeping All Students Safe Act to protect students from dangerous restraint and seclusion on December 16, 2011. The bill will establish vitally-needed national minimum standards to protect all school children nationwide.

Under Senator Harkin's bill, physical restraint will be prohibited except in emergency situations when there is an immediate threat of serious bodily injury. The bill bans seclusion of children in locked rooms or rooms from which they cannot exit. It bans life-threatening restraint that interferes with breathing or the ability to communicate, and mechanical and chemical restraints. It requires schools to notify parents within 24 hours of restraint. If there is imminent danger of harm staff may only use the degree of force necessary to stop the threat of harm. It requires the collection of data to improve decision-making and provide the public with information about practices long kept secret.

**Please ask your Senators to Cosponsor S. 2020, the Keeping All Students Safe Act, by emailing them at <http://1.usa.gov/Senate>. For more information, go to <http://www.autcom.org/policy.html>. We need to build cosponsors for Senator Harkin's bill.**

AutCom has worked very hard in support of

Senator Harkin's restraint/seclusion bill. We are leading efforts with the National Disability Rights Network (the national organization of Protection & Advocacy Agencies) and the Council of Parent Attorneys and Advocates to gather organizational support for the bill. At present, we have nearly 200 organizations in support.

AutCom has also written our own letter of support for the bill, at: <http://www.autcom.org/pdf/AutComLtrSupportHarkinBill1.pdf>

We also have a 2 page summary of the bill and what it would do at: <http://www.autcom.org/pdf/AutComSummaryS2020.pdf>

In addition, AutCom has published *How Safe Is The Schoolhouse? An Analysis of State Seclusion and Restraint Laws and Policies* by Jessica Butler. The report analyzes the S/R laws in the 50 states and D.C. and how they protect students with disabilities. It examines their strengths and their weaknesses. There are 29 states with meaningful protections in statute and regulation, compared to 22 a few years ago. *How Safe Is The Schoolhouse* is the only current compilation of state restraint and seclusion laws and policies. There are easy-to-use charts and maps, as well as summaries of each state's law at: <http://www.autcom.org>. Click on **New AutCom publication: How Safe Is The Schoolhouse?**

## Time to Renew your Membership!

(See Form on Page 15)

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**Web Site: [www.autcom.org](http://www.autcom.org)**

# What's Wrong with ABC's 20/20 Picture?

Institute on Communication and Inclusion, Syracuse University School of Education

On January 6, ABC's 20/20 a story about a family in Michigan that had been torn apart by allegations that the father had sexually abused his daughter who has autism. The allegations purportedly came from the daughter herself while typing with the support of a facilitator, using facilitated communication.

The show concluded that the police and district attorney in the case grossly violated accepted practices of investigation and victimized the father, the father's son, and the family. The show also implied that facilitated communication is an invalid method for supporting communication and that the daughter in this family is certainly illiterate.

Unfortunately, ABC's 20/20 failed the most basic principles of fairness in its own reporting:

- It provided no full explanation of facilitated communication from researchers or practitioners who have championed the method.
- It failed to explain that there have been articles, books and standards for the practice of facilitation, including ones that specifically address how to respond to sensitive allegations.
- It failed to explain the goal of facilitation, namely independent typing and/or a combination of speaking and typing, and that a number of individuals have achieved this level of communication competence.
- It provided a description of the method that is directly contradictory to definitions of the method in the standards. For example, the reporter states that a facilitator "helps [the user] move her hand to the letters so she can type out her thoughts." In fact, the facilitator provides backward resistance, never guiding the hand toward the letters.
- It failed to explain that individuals who have achieved independent typing or who have passed assessments of their typing competence have trained with multiple facilitators, including their own parents and family members, but also teachers, speech/language pathologists, and others.
- Perhaps most importantly, it failed to alert viewers to the fact that there is an extensive body of research literature in which the method has been validated, including research that involves video eye-tracking showing that

the subjects gazed at letters sequentially before ever moving the hand to type them (Grayson, Emerson, Howard-Hones & O'Neil, 2011), linguistic analysis demonstrating that the individuals with disabilities employ significantly different patterns of word use than their facilitators and that they were different from each other even when sharing the same facilitator (Zanobini & Scopese, 2001; Tuzzi, 2009), evidence of speech before and during typing (Broderick & Kasa-Hendrickson, 2001; Kasa-Hendrickson & Broderick, 2009), and message passing, where individuals demonstrated authorship by conveying information that was masked from the facilitators (Cardinal, Hanson, & Wakeham, 1996; Sheehan & Matuozzi, 1996; and Weiss, Wagner & Bauman, 1996). In contrast to the message passing test shown on the ABC story, in each of the research studies noted here, individuals with disabilities demonstrated the message passing ability only after multiple practice sessions; it is possible that with familiarity with the process of this assessment, the individuals became desensitized to anxiety associated with being so assessed.

- And it neglected to mention that the one scientific study that has been conducted on facilitated communication and allegations of abuse found that the patterns of disclosure of abuse via facilitation follow precisely the pattern seen with children who speak, showing that in approximately 1/3 of the allegations there is corroborating evidence including physical evidence, in 1/3 of the allegations it is unclear whether there is sufficient evidence to proceed with legal action, and in 1/3 of the cases the allegation proves unfounded (see Botash, Babuts, Mitchell, O'Hara, Lynch, & Manuel, 1994).
- In its report, ABC properly notes that the police did not bring in a "naive" facilitator (someone who was not privy to what the person with autism had purportedly communicated regarding abuse.) The purpose of this approach is to see if the person repeats the content while typing with the support of the second facilitator. If the person fails to

produce the content, one does not know if the original content came from the person or not. If the person reproduces similar content and language, then it rests with the courts to decide on the veracity of the content. However, ABC failed to mention that the Facilitated Communication trainer who had first introduced the method to the family insisted, to no avail, that the prosecution team bring in a naïve facilitator and would not accept the allegations as best practices were not followed.

It is disappointing that ABC presented such a one-sided view that does not accurately reflect the method, the research or the standards of best practice. A statement summarizing the research and references to the studies cited above can be found at:

[http://soe.syr.edu/centers\\_institutes/institute\\_communication\\_inclusion/Research/authorship\\_and\\_controversy.aspx](http://soe.syr.edu/centers_institutes/institute_communication_inclusion/Research/authorship_and_controversy.aspx)

[http://soe.syr.edu/media/documents/2011/6/Research\\_Supporting\\_Authorship\\_version\\_22.pdf](http://soe.syr.edu/media/documents/2011/6/Research_Supporting_Authorship_version_22.pdf)

The reference for the research on reporting of sexual abuse allegations is:

Botash A.S., Babuts D., Mitchell N., O'Hara M, Lynch L., Manuel J. (1994). Evaluations of children who have disclosed sexual abuse via facilitated communication. *Archives of Pediatric Adolescent Medicine*, 148(12):1282-7.

## From Being a Skeptic to a Supporter of FC

by Karen Mirochna

"Facilitated Communication. Another hoax perpetuated on parents desperate to give their child a voice."

Those were my thoughts after seeing my first demonstration of FC. As a teacher consultant for an intermediate school system, I was surrounded by supervisors, principals, speech and language therapists, and teachers who supported and reinforced my view.

The most prevalent opinion was that the composer of the typed messages was the facilitator. Sometimes those who were "typing" were not even looking at the keyboard. I was opposed to even trying such a blatant fiction with anyone on my caseload. I certainly was not going to encourage parents to use it with their child.

It was late in my career that my feelings began to change. I tried FC (in secret) with a student who had no speech but appeared to be able to read. At first I tried only "yes" and "no". It seemed to work. I was prepared to move forward when his parents



Kayla Takeuchi (R) with her mother, Nadine, is a FC success story personified.

put a stop to this experiment. I just shrugged and thought it was probably for the best. I thought I was losing my perspective - being taken in.

Another student was silent but definitely reading. She was immediately able to type words on the computer. Yet it had been assumed she was mentally impaired. I was wavering. Were these isolated cases?

Finally, Sandi McClennen talked me into going to an AutCom conference in Ann Arbor. I went and I was amazed. I saw people typing on their own - people who had previously been facilitated. I think Jacob Pratt made the biggest impression on me. He was definitely on the autism spectrum, but he was typing on his own and the message was reflected onto a screen. I could see what he was typing as he typed it. He was a college student. I saw people who had severe autism, with stereotypies, typing with various degrees of facilitation: hand over hand, hand under elbow, hand on shoulder, no hand at all.

This was not a hoax. Instead it was chance for people who were nonverbal to express their wants, needs, thoughts, and ideas.

Since then, I have become a proponent of FC and of AutCom. I grieve the chances I missed, but I am now taking every opportunity to recommend FC to parents, teachers, and others I meet.

**"I have learned to use the word  
'impossible' with the greatest caution."  
- Wernher von Braun**

## ***Autism Without Limits – A 2012 Conference Snapshot*** by Anne Bakeman

It's hard to describe the experience of an AutCom conference: the energy, the diversity, the unpredictability! People ecstatic -- and nervous -- to be meeting again or for the first time, jumping up and down in empathy, vocalizing a reply or slowly typing questions and commentary. The absolute silence of an audience straining not to miss a word, and the ensuing buzz of talk mingled with the clicks of communication devices. Hopeful parents, there because they want to hear from the "experts" what they already suspect: that their children are smart and capable. Teachers and caregivers wiping their eyes in relief, given permission to believe in their charges' competence. The dance of recognition and acknowledgement going on in the back of the room where someone is too excited to sit, too engaged to leave.

On a flawlessly sunny California day, the festivities begin with a welcome by the deputy mayor of Los Angeles. Then comes the keynote, "Autism Without Limits," by Californian Sue Rubin, who has typed: "Before I could type to communicate...words floated over my head but I didn't hear them. I quite believe I was retarded, if you define that as not being able to think." She tells about school and the behaviors that so often got in the way, her prize-winning essay on Cesar Chavez and the subsequent LA Times and KCET Emmy-winning story about her. ("I believe that a successful experience like that creates a mindset that allows me to go from success to success in spite of really awful autistic behaviors that I still experience.") She explains about moving away from home and living now with the support of paid staff, attending college, developing relationships and maintaining them over time, the making of the Academy Award-nominated documentary "Autism Is a World," her luck at being able to keep her living supports in this economy, and learning to "rise above" the behaviors and "realize there are no limits."

As usual, the several breakout session choices are state-of-the-art. Don Cardinal is speaking on the topic "Demystifying FC: An Ultra-Close Look at the Practice of FC." Dana Commandatore is inviting her audience to think about "Rethinking Autism." Steven Kapp's title, "Evaluating the Neurodiversity Movement: History, Progress, and the Path Forward," sounds equally intriguing. I opt for Peyton Goddard's presentation, "Treading Each Treason and Treasure



Donna Downing (R), AutCom's new president, and her son, Mike Hoover, an experienced self-advocate (L)

in a Troublesome World," which reminds me of an e. e. cummings poetry reading in the way she plays with words, coining them when necessary to exactly fit her meaning. Something she has said so moves audience member Chris that he is obliged to leave the room - followed by Peyton! The two of them settle on the floor in the hall and converse via letterboard and iPad for ten minutes or so while others carry on the presentation - after which they both calmly re-enter and resume their roles as presenter and audience member.

In Stephen Hinkle's plenary session, "The Hidden Social Curriculum," he strides confidently around the room orally riffing on his slides: the myth of the person as wishing to be alone, the challenges to social interaction (e.g., sensory sensitivities, anxiety, movement differences), the need to explicitly teach and support development of skills - not in isolation but in inclusive school and extracurricular settings; the barriers faced by students on the spectrum. The audience gets some hands-on practice task-analyzing a "hidden curriculum" scenario, thus exiting the session with ideas to use in real life.

Another breakout offers another tempting array. "Communication: Bring It On!" is the title of Darlene Hanson's animated session. Next door, Lars Perner ("Things They Would Not Teach Me in College") offers his audience tips on navigating the academic environment. Down the hall, Rob Cutler and Mike Hoover present the essays they've typed on the topic, "How to Get the Life You Choose," including the cultivating of political consciousness and activism; while across the way Jordan Ackerson and his mother Lisa Lieberman are addressing

the process of "Learning Self-Advocacy Skills: Exploration of Issues from the Advocate and Parent Perspectives" in adolescence and young adulthood. All of this timely and relevant information comes to us by way of true experts.

After dinner we are entranced by a live dance and mime presentation, "God Does Not Make Garbage: A Dialogue in Our World" by Johnny and Chris Seitz, accompanied by a moving poem written and read by Beau Sia. And so the first day ends, my brain and senses full, the creative juices flowing.

Saturday morning's plenary presenter, Anne Donnellan, has us rethinking autism, teaching us again that people's sensory and movement differences can make it appear that they "(do not) possess concepts like thinking, feeling, pretending, dreaming and imagining..." as Simon Baron-Cohen asserts. "We make things up, then get together and declare it the gold standard," Donnellan says, when all we are doing is assessing our experience of people on the autism spectrum - not their experience of themselves. We learn that acquired neurological symptoms can result in developmental differences: "akinesia" can be seen as "non-compliance," "festination" (accelerating rhythm) as "behavior excess," "bradykinesia" (slow movement) as "mental retardation," and tics as "aberrant behavior." In order to support people effectively, we need to personalize (not just individualize) our approaches; we need not only to presume, but to look for, competence. "We have to stop pretending we know and learn to listen," we are reminded. What better time than now, while the very people who can tell us are in our midst.

Another remarkable variety of breakout sessions follows: Darlene Hanson outlines "A Process to Independent Communication," a panel of parents shares tips for "Raising an Empowered Self-Advocate," and Jeremy Secile-Kira tells about having "A Full Life with Autism." I decide on "Rated R: That Oh-So-Difficult Topic" with Nick Pentzell, Hope Block and Jacob Pratt. Nick and Jacob (who is engaged to Hope) were unable to attend, so the presentation is a carefully choreographed pas de trois, volunteers reading the scripts sent by the two men while Hope's device reads what she has typed and is typing spontaneously. These three impassioned, funny and perceptive people have summoned the courage to share their innermost desires and fears - as well as the no-nonsense ideas they have come up with for hurdling the barriers between themselves and their goals. The ongoing conversation is so altogether forthright, serious, and myth-busting,

### Rob Cutler's Comments On The Conference

I HAD A GOOD CONFERENCE. OUR PRESENTATION WENT WELL. ME AND MIKE ARE A GOOD TEAM. WE ARE ALIKE IN OUR THOUGHTS AND WE ARE BOTH HONEST. OUR PRESENTATION WAS SMALL BUT PEOPLE WHO WERE THERE WERE VERY INTERESTED IN OUR WORK OF TAKING CONTROL OF OUR LIVES. WE GAVE HOPE TO SOME WHO HAVE SMALL CHILDREN AND I THINK WE SHOWED THEM WE CAN BE SUCCESSFUL IN OUR LIVES. YES .

that it knocks our collective socks off.

I replace my socks and head for the afternoon plenary, "Properties of Supportive Relationships from the Perspective of Individuals on the Autism Spectrum" (with Jodi Robledo and panelists Sue Rubin and Stephen Hinkle), a discussion of the nature and quality of lasting relationships. Sue describes the process: "It's almost as if you marry someone and divorce a year later!" All speak of the constant anxiety of having to re-develop a relationship, not knowing if it will work. We learn that a successful relationship must be dynamic and reciprocal, and the effort put into it is complicated when there is an additional "intertwining of lives" (as in child-rearing); it must work "organically." The audience-interactive session ends with a quote from the late Herb Lovett: "The quality of the relationship may be the most critical feature in education, intervention, and support. Techniques and strategies alone are not sufficient." Indeed.

In the final breakout, Kayla Takeuchi relates her personal quest, "The College Dream Comes True." DJ Savarese's film project, "Art as Advocacy: Finding Our Voices," is a hit. Both these talented young people use typing to communicate. Steven Gersten, a lawyer and staff member in LA Mayor Villaraigosa's office and diagnosed with Asperger's, speaks with expertise on "Creating Successful Environments for Individuals with Autism." It's hard not to notice again the diversity of experiences and perspectives represented.

"The Last Word," a conference tradition, gives

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Conference Snapshot continued)

presenters who are on the autism spectrum a chance to comment on what has been said and left unsaid. Afterward, there's a last chance to buy the one book or DVD you don't have in your library and the raffle tickets you need to win the Hollywood movie basket or the handmade afghan (just two of the many

terrific donated prizes), and then it's time for the drawing. People linger, reluctant to leave, hanging on the words, talking, typing, communicating in other unconventional ways - wanting, I suspect, to savor the positive energy generated by this gathering as long as possible. I am no exception.

**The "Last Word"  
by presenters  
on the autism  
spectrum ends  
every  
conference.**



## Massachusetts Takes Another Look at FC

by Barbara Cutler

Because a graduate student at a local university objected to including facilitated communication (FC) in the proposed Alternative and Augmentative Communication (AAC) revisions to the Massachusetts (MA) Regulations for Teacher Licensure, the MA Board of Education (DOE) was deleting FC until Julie Landau, Esq., of the MA Advocacy Center for Children put in a call to Barbara Cutler.

Landau asked Cutler if she could present at the hearing on the proposed revisions in defense of FC before the week was out. She would be the only one supporting FC and her testimony would be limited to 3 minutes, a heavy challenge in a state where its Dept. of Mental Retardation (DMR) (now known as Dept. of Developmental Services - DDS) issued its only advisory ever against FC as dangerous to the individual, a Department which allowed MIT to conduct an experiment in the 1940s-50s feeding radioactive cereal to institutionalized children to study the way the body absorbs calcium and iron, and a Department which, when psychotropic drugs became available, made heavy use of those drugs.

Now DOE was offering an opportunity to chip away at the often hostile resistance to allowing people to communicate through FC. Cutler decided to use her 3 minutes to list the accomplishments of her son Rob because he had access to communication using FC, and there followed a litany:

Rob became President of the Autism National Committee. Rob has served on the State Committee of the Mass. Dept. of Mental Retardation. He can

tell his doctors which medicines work for him and which don't. He has presented at conferences for medical students. He can talk with his counselor. He can mentor troubled students in South Boston.

The DOE Board was given a package of documents with a cover listing Rob's curriculum vitae, Barbara Cutler's curriculum vitae, and samples of Rob Cutler's FC communications including his testimony in PILCOP's Amicus Brief in the Olmstead Case before the Supreme Court, a poem (the Road to Recovery), a conference presentation, an address to 3<sup>rd</sup> year medical students, a short letter to legislators, and legislation Rob filed to "Protect Persons with Disabilities."

Also submitted were letters of admiration from the staff of the Carl & Ruth Shapiro Family Foundation, Michael Dowling of Medicine Wheel, the DMR Director of the Office of Citizen Action, and staff of the Horace Mann Education Associates. Documents supporting FC included the NH Task Force on Autism Assessment & Intervention, the AutCom pamphlet "Seeing Movement," and the Communicator issue covering Rob's being honored by the MA Senate "in Recognition of Outstanding Community Service on Behalf of People with Intellectual and Developmental Disabilities."

At the end of her 3 minutes Cutler gave the DOE Board a copy of Sharing Our Wisdom, explaining that articles in this book by Rob and many others on the autism spectrum would give them the best information about FC and autism available to them.

Because of the rush to present, Cutler was able to put together only one packet of documents. At the end of her presentation one Board member rushed up to ask to look at the book and received it for the Board.

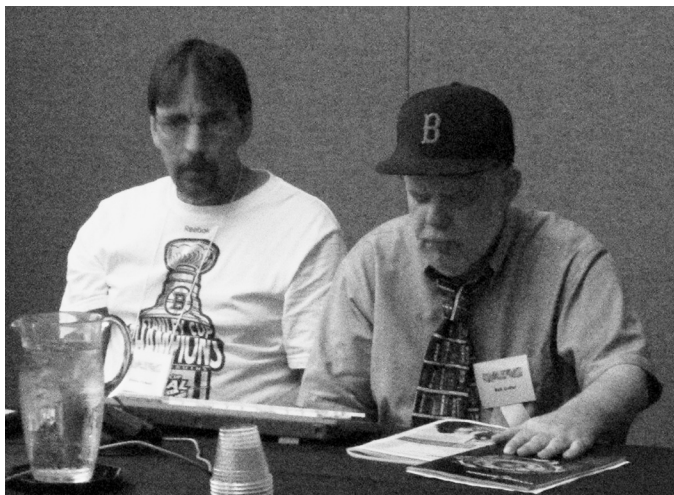
A week passed before Julie Landau emailed the Cutlers: "Thank you for your fabulous presentation to the Board of Ed - it was so powerful and really

made a difference. We are very pleased that the Board directed the Department to include FC in the guidelines that will be used to approve teacher preparation programs, after referencing your testimony."

Now we need to ensure that the Board's support for FC moves from paper to implementation.

## How to Get the Life You Choose

by Rob Cutler



Rob Cutler (R) and Steve Powell

I COME TO CALIFORNIA TO PRESENT WITH MIKE HOOVER. MIKE HOOVER IS A GREAT MAN WHO LIKE ME GOES TO THE STATE HOUSE. HE IS OUR WEST REPRESENTATIVE WHO DOES WORK LIKE ME. WE MAKE A GOOD TEAM.

I WANT YOU TO KNOW THAT I HAVE COME FORWARD IN LIFE BECAUSE I HAVE FACILITATED COMMUNICATION. FC HAS PROVIDED ME THE TOOL I NEED TO GAIN FREEDOM FROM CONTROLLING GROUPS. FC HAS GIVEN ME A VOICE. FC IS REAL. WHERE ONCE I WAS SILENT, I CAN LET PEOPLE KNOW MY FEELINGS. WHERE ONCE PEOPLE WOULD MAKE DECISIONS FOR ME, I NOW MAKE MY OWN DECISIONS. I CHERISH MY FREEDOM.

MY WORDS HAVE A VOICE. IT HAS CHANGED MY LIFE. I CAN TYPE OUT MY NEEDS AND DESIRES, BUT BEFORE FC I WASN'T LOOKED AT OR RESPECTED. FC IS A TOOL OF POWER. I NOW HAVE FREEDOM TO RUN MY LIFE, AND THE WORLD OF MINE IS BETTER.

I TYPE TO LET DOCTORS AND THERAPISTS KNOW WHAT IS ON MY MIND. I AM HAPPY THAT WE HAD TWO GOOD APPOINTMENTS WITH DR. THALL AND DR. HARDY. THEY LISTENED TO ME AND DID NOT CHANGE MY MEDICINE. THEY NO LONGER HAVE TO GUESS. MY TYPING TELLS THEM.

KNOWING HOW TO TYPE TOOK ME TWO YEARS OF TRIAL AND ERROR. I CAN ONLY TYPE AS MUCH

AS MY BODY ALLOWS ME TO DO. SOME CAN ONLY DO A LITTLE WHILE OTHERS CAN WRITE BOOKS. A LITTLE TYPING IS BETTER THAN NONE. THEY SHOW THE WORLD THEY HAVE THINGS TO SAY EVEN THOUGH THEY MAY NOT BE ABLE TO SPEAK.

I THINK A TIME WILL COME WHEN FC USERS WILL TEACH OTHERS HOW TO FC. I DREAM OF THIS DAY FOR THE SAKE OF THE VOICELESS PEOPLE. YES, I WANT TO ADVOCATE TO HELP PEOPLE WHO CAN'T COMMUNICATE TO HAVE A VOICE.

I WANT TO THANK EVERYONE WHO HAS KEPT ME SAFE THIS YEAR. I WANT TO THANK MY FAMILY AND FRIENDS WHO HAVE STUCK BY ME ALL THESE YEARS FOR HELPING ME HAVE ANOTHER SUCCESSFUL YEAR. I AM SO GLAD TO HAVE A LOT OF FRIENDS WHO HAVE SEEN ME GROW TO BECOME THE MAN I AM.

I HAVE MUTUAL RESPECT WITH THALIA. SHE IS MY COUNSELOR AND MY FRIEND. THALIA HAS TAUGHT ME THAT I CAN SAY WHAT I WANT AND IT WILL NOT OFFEND HER. I CAN BE HONEST. I DO NOT HAVE TO BE QUIET AND LET THE WORLD GO BY; I CAN VOICE MY OPINIONS ABOUT A LOT OF THINGS. SHE HAS SHOWN ME I CAN HAVE MY OWN OPINIONS. I CAN LEAD.

WHEN I GET TO SING WITH THALIA, I GET TO PUT MY TROUBLES AWAY. THE SINGING MAKES ME FEEL HAPPY INSIDE AND THE WORLD IS A HAPPY PLACE. MUSIC IS WONDERFUL. IT MAKES MY SOUL SMILE.

I AM HAPPY THAT I GET TO SEE BONNIE. BONNIE IS A GOOD WOMAN AND I AM PROUD TO TALK ABOUT HER. SHE IS ALWAYS IN MY THOUGHTS. WE HAVE BEEN THROUGH A LOT AND WE UNDERSTAND. YES. SHE IS THE SPECIAL ONE IN MY HEART AND WE ARE HAPPY WHEN WE ARE TOGETHER. YES. I WILL SEE BONNIE ON MONDAY. I LIKE THAT I SEE HER EVERY WEEK. IT IS A NICE WAY TO START MY WEEK. I KNOW BONNIE LIKES TO SEE ME TOO. WE HAVE A LOT IN COMMON AND I FEEL WE WERE MEANT TO BE FRIENDS FOR LIFE. YES.

SOMETIMES I GET STUCK. IT'S LIKE THE BODY IS FROZEN BUT LIFE KEEPS MOVING. THEN I CAN ONLY

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Rob Cutler continued)

TYPE AS MUCH AS MY BODY ALLOWS ME TO DO. I HAVE NOTICED THAT AFTER A RAINFALL MY BODY CAN MOVE BETTER. I BELIEVE AIR QUALITY AND ALLERGANTS PLAY A MAJOR PART IN MOVEMENT.

I WANT TO BE A GOOD MAN AND I WANT NOT TO FEEL RUSHED BY MY STAFF. THEY NEED TO RESPECT ME AND TREAT ME AS AN EQUAL. I AM NOT HAVING SEIZURES BUT I FEEL RUSHED SOMETIMES AND IT MAKES MY MIND RACE AND THEN IT IS HARDER TO MOVE. DON'T RUSH ME. I WANT TO STAY IN A CALM MOOD. RUSHING MAKES ME ANXIOUS. GETTING READY EARLY FOR AN APPOINTMENT IS GOOD. IT MAKES ME FEEL LIKE I AM NOT RUSHED. YES. I AM THANKFUL FOR MY TEAM WHO KEEP ME SAFE.

I LIKE TO SEE GEORGE (brother) AND FRANK AND THE OTHER GUYS AT GEORGE'S OFFICE. THEY TREAT ME LIKE A MAN WHEN I GO THERE. I FEEL THEIR WARMTH. YES.

STEVE AND I HAVE SPENT MANY BIRTHDAYS TOGETHER AND I HOPE WE HAVE MANY MORE CELEBRATIONS. WE ARE GETTING OLDER TOGETHER BUT WE ARE NOT OLD YET.

I HAVE BEEN MENTORING YOUTH IN SOUTH BOSTON AND CAMBRIDGE WHO LEAD TROUBLED LIVES. I AM GRATEFUL FOR THE OPPORTUNITY TO WORK WITH HUNDREDS OF KIDS SINCE WE STARTED IN SOUTH BOSTON HIGH SCHOOL 10 YEARS AGO. THE KIDS GET TO HEAR ABOUT HOW I HAVE STRUGGLED. I TELL THEM I CAN SHOW THEM THAT WITH RIGHT SUPPORTS IN THEIR LIVES THEY TOO CAN BE SUCCESSFUL. I TRY TO CHANGE THEIR VIEW OF THE WORLD AND I TRY TO GIVE THEM HOPE. THE KIDS ALWAYS AMAZE ME. THEY MAKE ME HAPPY TO BE THEIR FRIEND AND MENTOR.

I HAVE LEARNED THAT MY JOB IS TO SHOW THERE ARE POSITIVE ALTERNATIVES THAT WORK BETTER THAN THOSE WHICH CONTROL AND DEMEAN PEOPLE. MY GOALS ARE TO PROMOTE PEOPLE WITH AUTISM AS THEY ARE—LOVING, CARING AND INTELLIGENT HUMAN BEINGS WHO ARE NOT BLIND BUT SEE.

I WANT TO VOICE MY OPINIONS OF ISSUES FACING PEOPLE WITH AUTISM AND OTHER DISABILITIES. I WANT PEOPLE TO HAVE A BETTER UNDERSTANDING OF AUTISM AND PEOPLE GETTING THE SUPPORTS TO LIVE IN THE COMMUNITY AND GETTING SERVICES. I AM PUSHING TO LET EVERYONE BE ABLE TO CHOOSE WHERE AND HOW THEY LIVE.

I AM HAPPY TO BE ABLE TO GIVE YOU MY OPINIONS. I HOPE YOU CAN LEARN FROM ME. I AM A SURVIVOR. LET'S ALL BAND TOGETHER. WE SHALL OVERCOME. THERE IS STRENGTH IN NUMBERS. IT IS HARD WORK FREEDOM FIGHTING. THANK YOU FOR LISTENING.

## Was Justice Served?

by Barbara Cutler

Jeremy Labrie was an 8 year old Massachusetts boy with autism diagnosed with non-Hodgkin's lymphoma, a type of cancer with an 85-90% cure rate. His mother, Kristin, a single parent, took him to the hospital for chemotherapy, and his cancer went into remission. He went home, and his mother was given prescriptions for necessary medications he was to be given at home. She repeatedly failed to pick up prescriptions, but led doctors to believe they were being filled, at one point asking for a liquid version of the medication because her son was having trouble swallowing pills. Without the medication, the cancer returned aggressively. In 2009 Jeremy died. He was 9 years old.

Kristin Labrie was brought to trial on charges of attempted murder, assault and battery on a disabled person with injury, and reckless endangerment of a child. She was found guilty. The judge spoke to the deceit practiced by Mrs. Labrie in causing her son's death, acts that were "extended, secretive and calculating" and which "chills one's soul." He told her there are burdens Society expects us to carry. He said that her crime demanded punishment and deserved a significant sentence but that that sentence should be tempered with mercy.

The defense argued that Kristin Labrie was no risk to society and not likely to commit further crime. Before sentencing, Mrs. Labrie addressed the court: "I am remorseful...wished I sought out more...miss my son every day..."

She was sentenced to 8-10 years in prison, 5 years probation and a program of anger management. Outside the courthouse, when asked by a reporter if she thought the judgement was fair, she quickly responded, "No."

Do you think justice was served?

**"For all those whose cares have been  
our concern, the work goes on,  
the cause endures, the hope still lives  
and the dream shall never die."**

**- Edward M. Kennedy**

## Mapping Charlie

by Jane Meyerding

### A Book Review by Anne Carpenter

The author, Jane Meyerding, is a woman on the autism spectrum in her early sixties who grew up in a Quaker family and has done some interesting things with her life including making teddy bears as a therapeutic activity, becoming a program coordinator for an agency and authoring a riveting book, *Mapping Charlie*, about a woman on the autism spectrum who isn't formally diagnosed.

Kay Schneider is a woman in her fifties who has worked at a University in Seattle and occasionally takes a class there. The job accommodated her needs, and she lived independently with Jim, her cat, in an apartment. All had been going quite well until it was discovered that a man named Charlie, another passenger on the bus she rode to work, was missing. They had once talked about the picture of a wolf on his t-shirt. Meyerding gives a vivid description of Kay's life with her need for routine and structure and order, her anxieties about the outside world, how she handles her job and living on her own.

Everything changes. One day, when Kay goes to her Latin class, Charlie Andriesen, also taking that class, has been murdered. He was last seen on a bus, talking with Kay. Because of Kay's odd behavior and the lack of understanding about her

as yet undiagnosed autism, she is suspected of having committed the crime. Things spiral out of control. She is fired from her job and exiled from campus. Kay swallows her anxieties and goes to the apartment that Charlie shared with his partner, Cee. Kay and Cee work together to try to crack the case, and they develop a friendship as he attempts to understand how having autism affects her mental and social functioning.

The author, having ASD herself, gives an excellent portrayal of how difficult it is for someone like Kay to pick up subtle social cues, especially in a complex relationship like the one she has with Cee. One can see the nuances of Kay's mind as she attempts to relate to Cee in a way that fits the circumstances.

The book is riveting from start to finish with real suspense as the case heats up. Kay's analytical ability is utilized to the max as she works with Cee to solve the mystery of Charlie's death and to track down and apprehend the killer. This book had some interesting twists to it, one being that Kay has face-blindness, something that is often seen in people with ASD, and another being her friendship with Osita, Cee's dog, raising the possibility of a service dog in her future. Wow!

## This Summer

by Chloe Rothschild

This was the summer I will always remember.

This summer was one like no other.

This was the summer that changed my life, for the better.

This was the summer where my world was turned upside down.

This was the summer where I once again came in contact with my written voice.

And this time, I stayed in touch with this written voice of mine, I didn't simply just say hello and goodbye and then hang up.

The line stayed open between us, we stayed connected.

Then it was through the use of this written voice of mine, that I let others hear me, and my opinions, and knowledge.

This was the summer of new beginnings.

This was the summer that marks the start of many great things to come.

This was the summer that gives me hope; hope for the future and for all things to come.

This was the summer I will always remember, forever and ever in the years that come.

This was the summer that started it all.

## White House Appointee Ari Ne'eman on the Power of Autistic Community

### Introduction to "Community Matters" by Steve Silberman

I've never been a fan of campaigns that propose to get people talking about important issues by telling them to shut up. (No "Day Without A Gay" in my name, thanks.) That's why, when I saw a press release [PDF] a year ago from an organization promoting a social-media blackout for autism awareness called "Communication Shutdown," it seemed like an awful idea. The goal of the event — touted by a roster of "celebs" including actor Steven Segal — was to give non-autistic people a taste of the frustration some people on the spectrum face in trying to communicate by convincing them to log off of all social networks for 24 hours (while downloading a \$5 "charity app" that funneled money to the organization.) It seemed almost perverse to honor autistic people by shunning the very medium that has empowered many of them to find their own voices at last, after decades of being silenced behind the walls of institutions and well-meaning organizations that claim to speak for them.

Then I read an inspiring post from a young woman named Corina Becker calling for a counter-protest on November 1 that she called Autistics Speaking Day. She wrote: "What's the tragedy? That people can't speak? Or that too few are listening? Whether we're verbal or nonverbal, does telling people to stay off social communication networks really create empathy for us? The Internet is how we find one another. It's where many of us feel heard. It's where many of us feel most comfortable." I offered Becker this forum for a day, and I'm glad I did. Her essay "25 Things I Know as an Autistic Person" was honest and provocative. Yielding this space to someone on the spectrum each November 1 feels like a tradition worth maintaining.

This year, I'm honored to feature Ari Ne'eman, co-founder of the Autistic Self-Advocacy Network, and the first openly autistic White House appointee, nominated by President Obama in 2009 to sit on the National Council on Disability. Ne'eman — who is also one of the youngest presidential appointees in history at 23 — is one of the most passionate and articulate leaders of the neurodiversity movement, an emerging force for social justice that brings the empowering message of the disability-rights movement to those who think differently. From his seat on the Interagency Autism Coordinating Committee, which oversees policy initiatives within the Department of Health and Human Services, Ne'eman has been a powerful advocate for autistic people and their families, fighting for services and support, inclusive

education, and public policy that will enable people on the spectrum to live and work in their own communities, while battling unethical research agendas and entrenched stereotypes of what autistic people can and can't do.

I did the first major interview with Ne'eman on Wired.com after he took his seat on the NCD, and have followed his career as I write my book on autism and the neurodiversity movement. Ne'eman and I don't always agree on everything, but I've often found myself mulling over things he says long after he says them. I've also watched him talk to autistic people and their families, to folks with other disabilities, and to student organizers and self-advocates across the country, and I've been consistently impressed with the depth of his knowledge, his compassion and empathy, and the earnestness of his commitment to civil rights for all. I'm grateful to him for speaking out today on the *Public Library of Science*.

### Community Matters by Ari Ne'eman

Community matters. One of the things I always appreciated about my first few weeks in college was the existence of the local Hillel — the Jewish student center active on my campus, and many hundreds of other campuses across the country. I was an out-of-state student going to a university where most of my classmates had grown up within no more than an hour's drive of the campus. Having an immediate sense of community as a Jew was incredibly meaningful for me — and yet, I always felt a profound sense of regret that I didn't have the same opportunities as an Autistic as I did as a Jew. Walking into the university disability services office was a far cry from the warmth of Shabbat dinner or outreach by campus Jewish organizations. Instead of being connected to others who could relate to my experiences as someone on the autism spectrum, I and other disabled students were usually greeted by a bored work-study student handing us a card upon which we could check one of a few "standard" accommodations — extended time, alternative print/braille, note-taking and a few others, crafted without thought to the needs of students like me. Anything else required a long wait and an uphill battle.

There are a lot of issues worth unpacking here — the low quality of support offered to disabled students in post-secondary education, the vast gap between programs focused around compliance and those focused around quality of life — but the one that I want to focus on today is the value of

community. Being part of any minority group is always a challenging experience. Living in a world built for people who are not like you is alienating, whether it's because of the way your brain works or because you don't celebrate Christmas. In the disability world, we use concepts like the social model of disability to explain this experience. Service-provision and reasonable accommodations and any number of other things we fight to receive are intended to bridge the gap between the world as it is and the world as we'd like it to be. Yet, we still have so very far to go to create a more just society. The last few months have seen some heated discussions about privilege in both the autism community (that is, the community of non-Autistic parents and professionals with an interest in autism) and the Autistic community. I think one of the things that makes privilege such a hard topic to discuss with those who are, or would wish to be, our allies is that it continues to exist, even when we get the things we're advocating for. In the best of all possible worlds we can create, we will still be expected to explain ourselves to others in ways that no neurotypical person would have to do. We will still frequently face assumptions and stereotypes that require us to work twice as hard for the same results.

So, what can we do when our best efforts to change the world we live in are simply not enough? What salvation exists for us, when our lives are still more difficult, even when we do get the supports and accommodations we want? These are vexing questions. Some people try and find the answer in the search for a "cure." They believe that the best way to solve the problems facing Autistic people is make us appear as non-autistic as possible, or to prevent future generations of Autistic people from existing.

The first option bothers me deeply. When a child or adult is called "recovered," they don't change into a different person. All the things — good and bad — that we call autism don't go away because you lose a word. Instead, that person no longer has language for what they experience. That person goes through the same struggles, the same difficulties, but lacks the context and the community to know how that it is okay for them to be who they are. Sometimes that prevents them from accessing needed help. Other times it just traps them in a place where they have to constantly look over their shoulder, worrying about who might notice them being just a little bit "off." Either way, it isn't an outcome we should wish

upon anyone.

Not too long ago, a colleague commented that I should be proud for being so nearly "indistinguishable from my peers." Only in the autism community would anyone consider that a compliment. Despite the good intentions behind the remark, I felt a profound sense of hate and disgust motivating it — not of me as an individual, but of the person I was growing up, and of the person I still am, hidden underneath layers of mannerisms and coping strategies and other social sleights of hand. Those kinds of statements define our worth as human beings by how well we do looking like people whom we're not. No one should have to spend their life hiding who they are.

As for the path of prevention, I've never seen that as particularly realistic. Not only because I like my brain the way it is and am worried about the ethical consequences of breeding "better" human beings, but also because I know that if people like me didn't exist, the stigma and prejudice that sometimes makes our lives difficult wouldn't go away — it would just move along to another group. Disability has always been a fluid concept, and I don't imagine for a moment that preventing the existence of the next generation of disabled people would or could eliminate the place we're put in within the social hierarchy. Besides, I think we have better solutions available to us.

To me, the better option has always been filling the gap between what we need and what we can get from society with each other. As we work to make the world better, we can provide ourselves with a place where we feel safe and understood, even if we don't yet feel that way in the broader society. Every time we speak up about what being Autistic means to us as opposed to those who speak on our behalf, we can empower other Autistic people to do the same thing. Every time one of us comes out of the closet in a place where people don't expect people with our kind of brain to be, we carve out a little bit more cultural space that we can claim for our community. What if the next generation of Autistic people grew up with the idea of Autistic community and culture an ever-present factor in their lives? What if we took our individual experiences and turned them into a collective narrative, as so many other minority groups have done across history? What if we knew, that even when life was hard and the world at large didn't understand, that we would always have the chance to connect with those of us who have gone

(continued on next page)

(Community Matters, continued)

through the same struggles? Whether it's through creating resources by and for our community - like ASAN's new *Navigating College* handbook - or just connecting with other autistic adults informally in social groups or online, I feel that Autistic community is and can be a revolutionary concept.

That is what Autistics Speaking Day means to me. For those of us who have spent our lives being discounted as voiceless or being told that our experiences don't count, the act of speaking

up matters. And while we should do it every day, this holiday gives us the chance to do it not only as individuals but as a community, to braid our individual narratives into a collective one. Most importantly, it sends a powerful message to any Autistic person who hears in the voices speaking up today an echo of their own lives: no matter where you are or what you're going through, you aren't alone. Community matters.

## Images from the Conference

Here are just a few pictures of presentors at this year's conference. One of the photographic challenges of an AutCom conference is our commitment to not using flash. For many of presentations, the darkened room needed for projecting on a screen made taking good photos very difficult, if not impossible.



For many participants, Darlene Hanson's presentation "Communication....Bring it On!" was a real eye-opener. Darlene introduced the iPad with Assistive Chat as a text-to-speech app. She also did an extremely helpful presentation on the process to independent communication, and joined Don Cardinal in "Demystifying FC."



Anne Donnellan, Ph.D. gave a keynote address on Sensory-Movement Differences and Disturbances



Johnny Seitz & Chris Rials-Seitz presented their dance "God Does Not Make Garbage - A Dialogue in Our World."



Lisa Lieberman joined her son, Jordan Ackerson, to present "Learning Self-Advocacy Skills from the advocate and parent perspectives."



Hope Block (L) gave a spirited and feminine rebuttle to Nick Pentzell's and Jacob Pratt's discussion of the problems surrounding sexual intimacy, a presentation that was first given at the 2010 AutCom Conference. Linda Rammler (R) provided technical support.



Dana Commandatore is an advertising director, author, blogger, disability advocate and mother to an autistic boy. Her presentation was titled "Rethinking Autism." She wants to shift the conversation from causation & cure, to improving the quality of life.



Sue Rubin (seated left) got the conference off to a good start with her keynote address "Autism Without Limits." Her mother, Rita Rubin, is standing with the mic.

**"All progress has resulted from people who took unpopular positions."  
- Adlai E. Stevenson**

## see me

by beau sia

(with help from johnny seitz and chris rials-seitz)

i live in a world  
that many do not  
understand.

without wanting  
to make sense of it  
on your terms?

they were taught ways  
which prevent them  
from seeing me.

can you let go  
long enough to understand  
that you must  
first let it be?

they see  
someone so different  
from what they know,

see yourself  
in the beautiful gifts  
before you.

that they do not see  
beneath  
the movements  
wrapped up  
in the poor definitions  
they've been given.

see the understanding  
that you crave  
in these gifts.

movement  
that is more  
than what they've learned.

see how beneath  
our movements  
lie the human-ness  
that  
connects us all.

movement  
that reveals  
so much more inside  
the child.

listen  
for more  
than what  
you've been taught.

movement  
that possesses  
a beauty  
most do not see  
through its presentation.

listen  
for what the body  
reveals  
is truly in the heart.

can you see this beautiful  
gift?

listen for  
the child  
that needs to be held  
by your child  
in order to grow.

can you be free of  
wanting to control it?

then see your reflection  
in the person  
before you.

be free of  
wanting to own its nature?

this child is not a what,  
but rather,  
a who.

be free of  
holding it as yours?

can you see  
this gift for what it is?

see him. see them all.

without trying to  
bring it down  
to your level?

## Thank you, AutCom Friends!

Now that Membership Renewal time is upon us again, we would like to thank all of you who have renewed or become new members of AutCom! Your support has enabled AutCom to keep our conference registration fees fairly affordable and to provide scholarship assistance to a number of individuals who otherwise might not be able to attend them - including the 2011 gathering in Burbank.

### AutCom Donors July – December 2011

We would especially like to acknowledge the following people for their donations above and beyond fees for membership:

Kyle Heffner & Josh Dominick (Youth Advocate Programs, Inc.) - These two young people organized a benefit concert and donated the entire proceeds to AutCom.

Anonymous  
Eric Bakeman  
Christine Bevilaqua  
Char Brandl  
Anne Donnellan  
Heather Hamilton  
Sandi and Doug McClennen  
Barbara Moran  
Phil Schwarz  
Emily Titon  
William Waltz - in honor of Nick Pentzell  
Barbara Welsh-Osga  
Fleur Wiorowski  
Laine Worrix

Thanks, too, to the many people who donated items for the raffle at our Burbank conference. The raffle ticket sales netted \$370 for AutCom!

Barbara Cutler's beautiful Autumn afghan was a big hit. If you were (or know who was) the lucky winner of this afghan, we would love to hear from you so that Barbara will know it went to a good home!

### Be a Member and a Donor!

On the next page is AutCom's membership form which also includes a space to indicate a donation. As a pioneer organization dedicated to the best interest of everyone in the autism community, whose members represent individuals, parents, professionals and care givers, we need your continued support. Thank you!

### 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.

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### AutCom Membership Form - 2012

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 with autism     Parent     Friend     Student

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

Enclosed is my membership fee of:     \$10.00 (person with autism)

\$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!

Please send the above information  
and a check with the appropriate amount in the enclosed envelope to:

Anne Bakeman, AutCom Treasurer  
3 Bedford Green, South Burlington, VT 05403

## Autism National Committee

Barbara Cutler  
7 Teresa Circle  
Arlington, MA 02474  
www.autcom.org



*Time to Renew or Join Today!*

We Need You Now

Membership form on page 15



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