



Volume 19, No. 1 - Spring 2010

THE COMMUNICATOR

A Publication of the Autism National Committee



**AUTCOM looks forward to going to
Wisconsin for our
2010 Annual Conference on October 15-16
*Communication, Competence,
Community:
Nothing About Us Without Us!*
Co-sponsored by
Autism Society of Wisconsin**

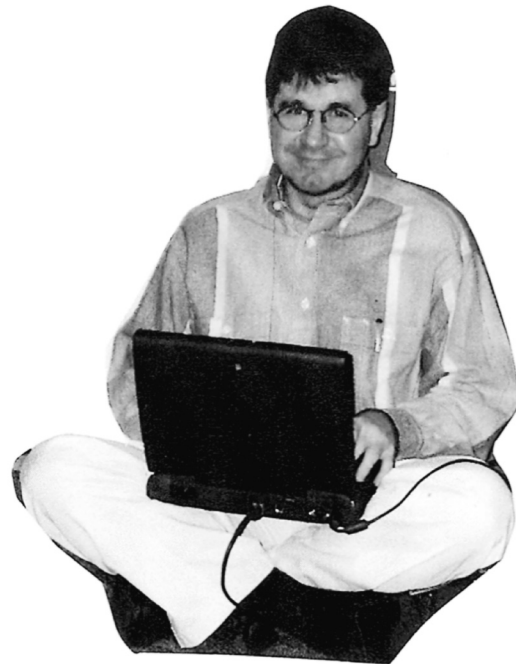
Judy Endow, author, presenter, consultant on ASD, will present *The Culture of Autism*.

Suzanne Oliver, Neurologic Music Therapist and Executive Director of Music Therapy Services of Arizona, will explain and demonstrate neurologic music therapy.

Paula Kluth, author, presenter, teacher, consultant, will show her film, "*We Thought You'd Never Ask: Voices From the Spectrum*," which explores the gap between the dominant discourse in autism and the stories of people on the spectrum themselves, and will moderate a group giving their perspectives.

Concurrent sessions will feature panelists on the spectrum discussing a range of topics from public policy advocacy to Sally Young's book, *Real People, Regular Lives*. There will also be an interactive artistic opportunity.

You won't want to miss it! A registration form is included in the newsletter. And make your hotel reservation now to assure you have a room in the conference hotel.



Herb Lovett, the first AutCom President - He taught us to listen!

CELEBRATING 20 YEARS

by Barbara Cutler

It was the summer of 1990 and the ASA Conference was over. We were sitting in the hotel coffee shop in Buena Park. We had lost. Our hard work for the ASA position to condemn the use of painful aversives would soon be rescinded for the so-called "parents' choice" which supported parents' "agreement" to the use of painful procedures against people with autism. Sue Pratt, the outgoing ASA President, had

(Continued on page 2)

Inside This Issue:

Page 5: Nick Pentzell - "Beyond FC"

Page 8: Two Book Reviews by Anne Carpenter

Page 10: Jacob Pratt - "Ground Rules for Panels with Speakers and VOCA Users"; Thumbs Up & Down

Page 11: Membership Form and the AutCom Principles

Page 13-15 Conference Registration Form, More Conferences, Books and In Memoriam

Web Site: www.autcom.org

(Celebrating 20 years continued)



Gunnar Dybwad, JD, Professor Emeritus

worked hard to get the Board to adopt that position. Now it would be undone.

We were a mixed crew of devastated professionals and parents sitting in that coffee shop: Ralph Maurer, Jayne Miller, Renee Whaley, Sue Pratt and me. Later that night we were joined by Jamie Ruppman. Any hope of equal protection or justice was gone. Was there anything more we could have done? Having allowed sufficient time for abject misery, I finally said, "We need to start another organization with the principles we believe in." Heads were slowly raised around the table, "Ya think?" Then not only Yes! but, "We must! We can't be silent."

Although we were all in agreement, I still asked for permission to move ahead to get an organization off the ground. Relieved that there was some hope (although little energy), the group stayed, supporting each other more in despair than hope. I went to my room, called Gunnar Dybwad and told him what we wanted to do. He responded, "There will be a check in your mail box when you get home. And call me."

Back in Boston I called Herb Lovett, filled him in and set up a meeting at Brandeis with Gunnar which included Martha Ziegler, then Director of the Federation for Children with Special Needs, the prototype of Parent Centers developing across the country.

We were starting from scratch. We needed officers, an incorporation and some members. The four of us present became the officers for the



Rob Cutler (Past President), Sue Lehr Ph.D. (Past President), Ralph Maurer, MD

corporation and first Board with Renee Whaley in Florida agreeing to become Treasurer.

I asked Herb to be President since up to that time he had not been directly involved with autism. He was not one for labels. "Why don't you be President?" he asked me. "Because I don't want the organization to look like we formed from sour grapes. I have been on the ASA Board and even ran this time, fortunately losing by a close number of votes." Herb and I had worked together days, nights and weekends for several years to support the passage of legislation prohibiting the use of aversives in Massachusetts, so we each knew the other's commitment to social justice. Herb accepted. We drafted our principles and moved ahead to gather supporters and to incorporate.

Letters went out and we quickly had 80 "founders" to support (morally at this time since we hadn't established dues) the new social justice group tentatively named, on Gunnar's advice, the Autism National Committee. We published our "founders" names in the first issue of *The Communicator*. Now we needed to move toward incorporation. Sitting behind Gunnar and me at a disability event was a lawyer, Alex Moschella, who was also active in the disability movement. He overheard our conversation about the newly forming organization, thought it worthy and offered to do the incorporation for us for free. And he did. We were born the same year that Congress passed the ADA.

The organization was to be a true parent-professional partnership - no professional advisory board. We would be equals. Little did we realize in 1990 how important self-advocates would be to AutCom's Board. First came Xenia Kathy Grant and Bonnie Forsythe, the first self-advocates to serve on



Jeff Strully (Past President)



Anne Carpenter (Past President) with Larry Bissonette

the Board. Next came Anne Carpenter and Robert Cutler. Our Board was moving quickly to a triumvirate of equal partners - parents, professionals and self advocates.

Our inclusion of self-advocates was more than window dressing. Robert Cutler sought and became the first self-advocate President of AutCom, a big challenge at the time for someone using facilitated communication (FC). He had a great support team of officers who valued his leadership—Jeff Strully, Rena Gans, and Sue Lehr. This was the AutCom mix—parents and professionals with a self-advocate leading. Rob convinced the Board to provide a different membership rate for people with autism since most have limited resources. Several trips to Washington for AutCom gave him the opportunity to speak on behalf of AutCom and people with autism.

Because Rob Cutler led the way, AutCom was able to support Anne Carpenter, another self-advocate, to be a successful President with good Board support. More recently, Sharisa Kochmeister, an FC user, became the third self-advocate to be President (of AutCom's nine Presidents to date). We are serious about partnerships.

In the past 20 years we have been able to attract some nationally known people in various disciplines to our Board, beginning with Gunnar Dybwad and Herb Lovett.

Herb brought in Michael Smull (Person-Centered Planning) and Bruce Dake (who translated our pamphlets into Spanish). We have had physicians serve—Ralph Maurer, Ted Eckberg, and Ruth Ryan; authors—Barbara Cutler, Paula Kluth, Lisa Lieberman, Dan Reed, Gail Gillingham, and Stephen

Shore; artists—Larry Bissonette, Bonnie Forsyth and Barbara Moran; leaders at universities—Doug Biklen, Anne Donnellan, Ann Turnbull, Jan Nisbet, Sandra McClennen and Sue Lehr; and others who have connected us with like-minded organizations—Pat Amos (TASH), Ari Ne'eman (ASAN) and Phil Schwartz (AANE).

First through Sally Young and now through Mary Schuh at University of New Hampshire Institute on Disability (UNH IOD), AutCom has operated a bookstore whose purpose is not for profit but rather to make available those books true to our principles (and only those books).

Since 1991 we have run annual conferences (except for 2001, the year of 9/11). At first those conferences were held just before or after TASH conferences for the convenience of some of our Board members, but then we began to collaborate with other autism organizations—Colorado, Georgia, Los Angeles, Pennsylvania, Edmonton (Canada makes us international), Michigan, UNH IOD and, for 2010, Wisconsin. Two independent conferences were held in Washington, D.C. At these conferences people on the spectrum have increasingly provided the information we need. Indeed, for the last few years they have closed each conference with "The Last Word" panel, rightfully commenting on the conference proceedings.

Although that first despondent group in Buena Park represented Florida, Kentucky, Michigan and Virginia (the "founders" covered many more states), AutCom was incorporated in Massachusetts and

(Continued on next page)

(Celebrating 20 years continued)



Barbara Cutler, EdD with Stephen Hyman, MD then head of NIMH, now Harvard University Provost - when AutCom attended meeting in DC

drew heavily on the North East Regional Conference on Autism (NERCA) for support and Board members. Like AutCom, NERCA was founded to meet a need, and like AutCom, NERCA's Board at the time was like no other, in that parents ran conferences for professionals.

NERCA was a group of parents in who, in 1972 after an ASA Conference in St. Louis, came together to find a way to get information to people in New England. Less than two months later, NERCA held



Barbara Cutler (L), Barbara Domingue (Original Board), Rob Cutlar (R) & Gunnar Dybwad (Rear) at a Circle of Friends meeting

its first well-received regional conference attended by over 300 people. In the '70s and even early '80s there were few or no regional conferences. Some of NERCA's featured speakers like Bill Condon were picked up by national conferences. A group of parents was ahead of the curve!

By the late '80s and early '90s there was an increasing number of state and regional conferences on autism. NERCA considered its logical next steps to be formally adopting social justice principles and having a seat on the Board of AutCom. AutCom was a logical extension of NERCA's principles and activities—cutting edge, getting the right information out, and social justice. Some of its members—Anne Bakeman, Barbara Domingue, Rena Gans, Alan Kurtz and Barbara Cutler—have served AutCom well as AutCom Board Members. AutCom's several conferences in New Hampshire have been well supported by Linda Flowers and by Louise and David Hackett, whose connections have brought about NH-ASA's formal adoption of AutCom's principles.

There are surely other AutCom names that should be here, but all of our Board members are stars—committed to social justice and the right of self-advocates to be heard. Although other organizations representing the strengths and needs of those on the spectrum (Autreat, ASAN, AANE) have come into being in the last 20 years, AutCom is the only truly equal partnership we know of—self-advocates, parents and professionals—and continues to move forward.

Well done, AutCom, well done!

Doug McClennen

**University of New Hampshire
Institute on Disability**

**12th Annual Autism Summer Institute -
A New View of Students with ASD:
Implications for Inclusive Education**

August 9-12, 2010

for information go to:

<http://www.iod.unh.edu/asi.html>



Nick Pentzell with facilitator Adam Lees

***Beyond FC:
Unlocking Codes of Social Cues to Open
Wider the Door
of Interpersonal Communication***
by Nick Pentzell

Since 2003, I have been a student at Delaware County Community College, where I take one course each semester. Last spring I declared myself a Communication Studies major. Part of this decision was influenced by my interest in primate communication -- especially that of the great apes: this major was a way of jump-starting my studies by examining how human primates communicate. However, I also realized that this major might help me improve my own communication strategies, as well as my ability to decipher neurotypical communication and help me improve the quality of my social relationships. There were times in my past, you see -- before I started using facilitated communication -- when I looked at human communication with a separation that in some ways made me feel akin to our great ape cousins. I think my interest in apes has a lot to do with growing up mute in a speaking world and gaining the use of language as a secondary means of interacting. Koko the gorilla, Kanzi the bonobo, and the chimpanzees and orangutans who have taken part in inter-species communication studies, in a way, share with me and many FC users a life-changing transition because of their acquisition of human language; like many of us on the spectrum, their intelligence was questioned until they proved they could communicate on human-neurotypical terms.

Introduction to Interpersonal Communication, my

first course toward my major, redefined my sense of what communication involves, and I would like to share with you not only some concepts I learned about neurotypical communication that I believe will enrich my social interactions, but also things I learned about my experience of autism and my process of acquiring language.

In a letter I wrote to my professor before I enrolled in his Interpersonal Communication course, I said that I saw my possible goals or outcomes as 1) improving my non-verbal cues and responses, and 2) interacting better with listeners. There were ways in which I learned how to improve these practical aspects, but my view of interpersonal communication was affected on a grander scale than mere "how-to" helpful hints. I felt like my understanding underwent a conceptual overhaul. I was challenged to address my own responsibility in the communication difficulties caused by my autism and to examine how my "disability" has affected not only my communication habits, but also my ways of thinking about communication.

Two ideas were most significant to me. The first involves the principle that "interpersonal communication is unavoidable": "No one cannot not communicate." Even when we do not overtly use language or gestures to communicate something we want understood, others make meaning from our behavior. This concept will be familiar to you, since autistic "behaviors" are forever being misread by neurotypicals, with interpretations about them that often are contrary to what we are experiencing or attempting to convey. The other idea that impressed me deals with the fact that there are structures inherent in communicating power and handling conflict; if we become aware of these, we can make antagonistic encounters more productive for ourselves and our communication partners.

Until I was thirteen and introduced to facilitated communication (FC), nearly all of my communication was non-verbal, instead of language-based. I sometimes vocalized a recognizable word or formed an ASL sign, but this was largely spontaneous, instead of planned, since speaking was so difficult for me. Non-verbal communication like grabbing someone's hand and taking the person to food that I wanted was usually clearly understood by the listener. However, my awareness of the world was much more complex and abstract than I could communicate non-verbally. For instance, I was misunderstood when I tried to indicate that I was not severely mentally

(Continued on next page)

(Beyond FC continued)

impaired, as everyone thought.

During my childhood, at worst I was labeled as unable to communicate - ridiculous (as I knew) and impossible (as I have said) according to communications scholars. At best, my ability was rated at about the level of a six-month-old baby. The real problem was that most people either did not recognize my non-verbal messages as communication and dismissed them as "behaviors" that had to be modified, or else they were somewhat aware that I might be trying to communicate, but the only way they could comprehend me was if I learned to communicate on their neurotypical terms using language-based systems. My attempted means of communication were not respected as equal to language and frequently were seen (or at least treated) as invalid, since intellect was not assumed and in many cases my non-verbalizing was not examined as relating to something I was trying to express. I suspect that if an anthropologist or primatologist had been placed in my Severely Mentally Impaired classroom to observe, she or he would have perceived the complexity of my own non-verbal communication and that of my classmates, as well as have seen a distinctive sub-culture in the classroom that escaped the notice of our teachers. Neurotypicals tend to assume that many animals have a greater capacity to communicate than do people who are labeled as having autism and "intellectual" or "developmental disabilities." The eyes of teachers, medical "specialists," therapists, and care providers need to be trained to observe us with the analytical intensity and accepting openness of people in the animal communication field. They should imagine themselves the Jane Goodall of their own fields.

Language-based communication had an aspect of coercion. I was taught only a few ASL signs that my hands could form, but these were not as natural or expressive as the sign language I had made up on my own and which people did not recognize as symbols of language but, instead, designated as "self-stimming." With only the few ASL signs that were understood by both me and a communication partner, I was limited to saying what I had been taught, not what I wanted to express. PECS, a picture-based communication system, had the same limitation: content was controlled by what pictures I was offered. (It was also insulting, since I was assumed to be illiterate.) Plus it was used one word at a time and always seemed artificial, like a task, rather than spontaneously interactive, like

language is supposed to be. My responses to verbal language were similarly controlled: most of the time I was expected to follow orders, therefore much of my language-based interaction with people was experienced as receiving commands and then getting praise or corrective instructions, depending on what I did. So, very often, I felt like I was being controlled, and I had little power in my life. Exercising non-compliance was a way I could feel I had some control.

I resisted communicating on neurotypical (NT) terms even after I accepted FC as a means of communication that I liked, because although I wanted to use the English language to participate in the NT world, it seemed that typing in English was a capitulation. So, for instance, for a while I refused to use silent "E"s in spelling, I sometimes made up acronyms - using the first letters of words in a sentence, instead of spelling them out, or I gave words idiosyncratic meanings. I still do these things once in a while, and I sometimes willfully misuse gestural sign language by loading one sign with many meanings that must be guessed. All the years that I was an unobserved huckle-buckle-beanstalk intelligent-being trying unsuccessfully to communicate what I meant, I felt like I controlled knowledge and meaning. I knew I was smart, and I knew I was communicating, but all the NTs who controlled me couldn't discern what I meant. When I learned FC as a means of verbal communication, sometimes I exerted power like Humpty Dumpty in Lewis Carroll's *Through the Looking-Glass*: "When I use a word," Humpty Dumpty said, in rather a scornful tone, 'it means just what I choose it to mean - neither more nor less.'

I made language mean what I chose. Or so I thought. People tried to tell me otherwise: "The question is," said Alice, 'whether you can make words mean so many different things.'

But my thinking followed this line: 'The question is,' said Humpty Dumpty, 'which is to be master - that's all.'

Other people's Alice-like reasoning - that language is transactional -- never made total sense before I took Interpersonal Communication last semester. Now it does. As I stated earlier, the first principle of communication is that it is unavoidable. The authors of my textbook, West and Turner, say that "we cannot prevent someone else from making meaning out of our behavior." One person does not control the meaning of symbols, since they are "mutually agreed upon by the participants in the

process." Maybe Humpty Dumpty was autistic.

I hadn't accepted the solipsism of my language control games, but now I saw that by obfuscating language I gave others control of the interpretation of my meaning. If I **really** want the greatest possible amount of control over what I mean, I must communicate as clearly and specifically as I can and engage with my communication partners to clarify what they decode from my messages, whether I use language or interact non-verbally.

It must be obvious by now that I am a control freak, perhaps understandably, given my past. Power seemed like it was a matter of having a strong effect, as in non-compliance, or like manipulation: making people do what I wanted, on my terms, especially if it wasn't their choice. This was as solipsistic and infantile as Humpty Dumpty. Although I had been maturing and understood that I have the greatest effect when I use language to explain, educate, and advocate, I found that in situations of conflict, I confused power with oppression. Even when I am in conflict with someone who is trying to empower me, I tend to resist their help because compromise, or even advice or guidance, feel like they are means of controlling me. It was no wonder that Humpty Dumpty sat away from everyone on a wall and fell to pieces when he came down from it. This is what entering the world of NT talkers can be like. However, developing a tougher shell or becoming hard-boiled might not help as strategies for communicating power and handling conflict.

West and Turner (Richard West and Lynn Turner, *Understanding Interpersonal Communication*) explain that power is drawn from different sources. **Referent power** is related to charisma. **Legitimate power** is derived from a position of authority. **Expert** or **information power** involves having knowledge that others want. **Persuasive power** means you can convince others to see your point of view. **Reward power** makes use of dangling the carrot, while **coercive power** makes use of the stick.

The latter two had comprised my concept of power, along with legitimate power; rewards and punishments were the behaviorist model of my early education, and authority, and especially coercive power, seemed the masculine model I was aware of in our culture and the kind I desired. However, as a non-speaking, small-statured man with a disability, I have no authority and can only threaten punishment by throwing a tantrum and abusing people. If I attempt this and refuse to accept rewards or persuasive arguments, the person I'm in conflict with

may have no alternative but to threaten punishment as well, and everyone is louder and bigger than I am. By acting out of control as my means of seeking power, I create a situation where I end up being overpowered by someone else. Probably for anyone coercion is not an effective power strategy but, for me, seeking coercive power always sets me up to fail.

My stepmom and I have a way of leveling the playing field when we argue. She becomes mute and we both have to write our words to one another in a notebook. We're allowed to say anything we want, no matter how terrible, but either one of us can stop the argument if we don't want to read what the other one is writing. She's usually more reasonable than I am and doesn't rise to the hook when I bait her to vent and be unfair (her level-headedness can be aggravating), but I realize in the years we've fought this way that she's been teaching me to use persuasive power. She always has accepted reasonable demands and explanations: I can change her mind and her understanding. It's twisted, though, that -- before I had a concept of persuasion as part of a power structure -- I never accepted it as more than a form of teaching. I hadn't really considered my expertise in various areas as power either -- nor my ability to flirt and charm -- although I was certainly aware how these boosted my self-esteem. Really, I have persuasive, expert, referent, and reward power at my disposal, and I recommend these as power sources to any other egg-heads who have a Humpty Dumpty streak.

I have described sources of power; now I'd like briefly to describe types of conflict. I tend to react to conflict as **relational** and get caught up in issues between me and my communication partner that may or may not have anything to do directly with the issue at hand. My control games are an example of this.

Often, aspects of **image conflict** enter the ring. With strangers who underestimate who I am, image conflict may be the point of the conflict itself. With people I know, image conflict is ancillary. For instance, occasionally my stepmom misunderstands my intentions and accuses me wrongly and I have to clarify her perception and set her straight before we can tackle and resolve the actual issue between us. There are other times, however, when I become self-punishing because I feel guilty about something and I manipulate the other person to get

(Continued on next page)

(Beyond FC continued)

angry at me so as to agree with my momentary self-image, but then I get angry at the status inequality (even though I have created it), so I escalate the conflict, then I hate how I am behaving, and I get depressed and shut the other person out to punish myself further. Now that I can recognize this self-defeating game I play, often I can avoid it and keep it from clouding a simpler type of conflict.

Only once in a great while do I come into **value conflict** - disagreements about what is right and wrong - with someone. **Content conflicts**, which are disagreements about issues, are usually the trigger for my disputes but, as I have demonstrated, I often layer image and relationship conflicts on top of this. However, it helps so much to be able to separate the different threads of the conflict so I can understand what is going on and what I can do to come out of a conflict constructively with a greater sense of resolution.

Before, conflict was not only a sensory and emotional upheaval, but also a nightmarish disruption of the world as I knew it. I could see the regular balance of my life from the other side of the looking-glass, but - bang as hard as I could - I couldn't get back to it, because I didn't know how I'd gotten to the topsy-turvy flip-side. Now at least, when I find myself there, I have strategies about how to get out.

Conflict can even be empowering when I'm able to stand my ground and effectively persuade, or when I listen and become more aware of my communication partners' needs and realize I can be the one whom people depend on. The best approach to conflict involves **symmetrical negotiation**, where both communication partners listen and offer suggestions. **I-Messages** - framing comments as "I think," "I need," "I feel" -- show I am responsible for my thoughts, feelings, and actions and I am not being accusatory.

My habitual emotional or psychological response about power may take time to change, but now that I can identify other sources and types of power, I can more easily step back and analyze the power structure of a conflict and try using a source or type that will lead to a desired result, rather than to an imagined feeling of control over a person or situation. People on the autism spectrum are said to have difficulty making sense of social rules. I think many autistic people's attention becomes focused on coping with their sensory sensitivities to the exclusion of the people around them, but some

studies suggest that there may be neurological causes that make it difficult to process social cues. Definitely, models and explanations of patterns make social and interpersonal communication rules more comprehensible and something that can be learned through study when it is not picked up by observation. Quality of life means developing social and intimate relationships by accepting and initiating interaction, including nitty-gritty tiffs and scraps.

FC has been empowering to many people on the autism spectrum, yet we stand apart in social awkwardness that might be lessened if we (and the people who care for and support us) were to learn to recognize the structural patterns of interpersonal communication and how to make our own communication habits more effective. I am only beginning to change my attitudes about and approaches to communication's unavoidability, and power and conflict issues, but in doing so I am having to examine what is learned habit and what is an organic part of the differences that autism makes in the way I perceive and communicate with others.

Beautiful Ben: My Son with Autism
by Sue Lehr
Review by Anne Carpenter

When Sue and Bob Lehr adopted Ben, they were told that he was a normal healthy baby, but they realized shortly after taking him home that something was not quite right. The large, placid baby laying in his crib, the gentle child who hardly cried, captivated them, and they were dedicated to keeping their precious Ben, no matter what.

As time goes on, the author and her husband become more and more aware of Ben's difficulties but are bound and determined not to have him in any segregated school placements for students with cognitive disabilities or in sheltered workshops when he reaches adulthood. Lehr and her husband also had adopted two girls, so Ben had two sisters without disabilities, which make for excellent social role models.

Their mission to help Ben is made more complicated by the times they were living in, when autism was much less understood and when most children with autism were placed in classes for children with cognitive disabilities and then referred to as having mental retardation. When Ben was in school, he had some caring teachers, but they, too, were bewildered by his challenging behavior and his habit of flapping his hands in front of his face. He

had limited communication, so no one was quite sure what he was trying to say through his behavior. The author describes the all-too common battles with the school district on behalf of Ben, as there was so little sympathy toward children with ASD in those days, which is still a sad reality, even in the 21st century.

Lehr documents Ben's struggles and successes through junior and senior high school, as he goes through a succession of both good and bad teachers, each one making either a positive difference or fostering a setback—often one very hard to recover from. Over the years, Ben continues to struggle with school, employment and housing, with triumphs followed by one setback after another. But in the end, he has his own furniture-making business, which is a stunning achievement in its own right.

The reader sees just how badly some school systems and agencies treat people with ASD, and the author pulls no punches. Her unflinching honesty and her sheer dedication to having Ben included in school, community and in housing makes this very disturbing yet powerful book all the more worthwhile.

***Opening Doors, Opening Lives
Creating Awareness of Advocacy,
Inclusion, and Education for Our
Children with Special Needs***

by Jennifer Greening

Book Review by Anne Carpenter

As the proud and loving parent of a child with autism and physical disabilities, the author writes about her daughter's schooling and the many attempts to exclude Marissa from opportunities to learn with other, "regular" classmates.

Greening begins the book with a description of Marissa's early childhood difficulties and her advocacy to get her daughter into an educational placement that would help her to learn and grow to her fullest potential. From very early in Marissa's childhood, the author faced battle after battle with the school system. Her daughter was placed in a special needs classroom but would come home from school sad and pale. Something was clearly wrong. The author saw how much her daughter was being held back, as she was nonspeaking and was in a classroom with only children who did not speak, so the classroom was silent. For good reason, the author did not feel that this was a good example for her daughter; she felt that her daughter would do

better in a general education class in which children talked to each other and where Marissa would have typical peers as social role models—the best kind! Throughout the book, Greening documents the many battles she fought and the incidents of abuse in the special classes, such as the time when Marissa was sent home because she wasn't wearing her shoes.

In every chapter and on every page, the author gives parents advice on how to advocate for their children, how to deal with the school system in a positive, non-combative way, and how to insure that the child's needs are met, every step of the way. This includes the child's medical needs, as Marissa has seizures as well as autism and problems with movement and coordination. This has made it necessary for her medications to be given at school. Greening is insistent upon having the child with a disability look good and be clean and presentable, to reduce prejudice as much as possible.

The author stresses the importance of behavior as communication, as she sees Marissa's challenging behaviors as ways of saying that the special classes did not meet her needs. And indeed, Marissa has fared so much better in the general education classes. I can't say enough about this excellent book. I love the author's positive outlook, her insistence on full inclusion, her belief in behavior as communication and her constant, practical advice. No parent of a special-needs child should overlook this book!

(Both these books are available in the AutCom Bookstore)



**Spring Sale at the AutCom
Bookstore!**

Save 10% to 20% on select products.

AutCom T-shirts now \$8!

Sale valid through June 30, 2010.

To browse our sale and clearance items, go to www.iodbookstore.com and select "Clearance Items" in the menu. Questions? Contact the bookstore at contact@iodbookstore.com or 1-800-378-0386"

Ground Rules for Panels with Speakers and VOCA Users

by Jacob Pratt

This article is about how to behave when on a panel or interacting conversationally with those of us who type to communicate. I just came back from an incredible TASH New England conference in which I was on both an evening panel and a panel that was doubled for the morning session the next day. The purpose of the double session was for those who do not use their own voices to communicate to have the time they needed to type. However, this is a problem when other panel participants don't listen to your typing or even know you are typing. Just as Hope Block (another panel member) and I had our facilitators sitting next to us, someone should have been sitting next to panelists with a vision disability to let them know when one of us is giving signs that we have something to say.

If our VOCAs speak, we need some ground rules, such as, "It is okay to not immediately stop talking so we can interject," because that would be just as rude as others completely ignoring us. However, it is important that, once someone hears the VOCA, to let us replay our message and, if necessary, go back to the topic the message refers to. This is because the message may be delayed due to the time it takes us to type it.

One of the things our group spoke about was the segregating language of the term "self-advocate," and that we who are involved in groups such as

AutCom and TASH are all advocates. One panel member has a t-shirt that says something like "SELF-ADVOCACY—TO BOLDLY GO WHERE EVERYONE HAS BEEN BEFORE." This says to me that when neurotypical people and people with disabilities want the same things -- inclusive education, supported lives in the community we choose, meaningful work and higher education opportunities, and love -- we are all advocating for the same things. Treating those of us who type on advocacy panels with the same deference and respect given to those among us who can talk would go far to eliminate a barrier within our own advocacy community.

Unless we are all typing to "level the playing field," we need to figure out ground rules amongst ourselves prior to being on panels or the discrimination of not listening to those who literally are voiceless will occur. If we really want to model neurodiversity, we need to model how each of us needs and uses individualized supports and accommodations. Otherwise the audience will only listen to those who speak (and who, therefore, may be perceived as "higher functioning." I am not accusing anyone of anything because I thought the advocates on the panel and those on the sidelines were very respectful. I just want everyone to be aware of what a disaster the panels would have been if they were not respectful.

Thumbs Down, Then Up

President Obama nominated AutCom Board member Ari Ne'eman to the National Council on Disability (the NCD), which deals with quality of life issues for people with disabilities, but that nomination requires Senate confirmation, and an anonymous senator placed a hold on it.

Thumbs Down to the anonymous senator placing the hold, blocking the nomination of the first person on the autism spectrum to the NCD.

Then Health and Human Services Secretary Kathleen Sebelius appointed Ari to the Inter-Agency Coordinating Committee (IACC) which addresses autism research. That appointment does not require Senate confirmation.

Thumbs Up to Secretary Sebelius and the Obama Administration!

Thumbs Up To

Mental Disability Rights International (MDRI) for their publication, "**Torture not Treatment: Electric**

Shock and Long-Term Restraint in the United States on Children and Adults with Disabilities at the Judge Rotenberg Center (JRC)—Urgent Appeal to the United Nations Special Rapporteur on Torture." We appreciate MDRI's courage in correctly naming what is happening there and wonder whether their publication will shame Judge Rotenberg and the governmental units that allow this travesty to take place in Massachusetts into stopping the torture that is occurring, mostly to people with autism.

Thumbs Up To

the House of Representatives for passing the Keeping All Students Safe in School Act. Now if we can get the Senate to pass Preventing Harmful Restraint And Seclusion in Schools Act (S.2860) . . . and both houses to apply the law to private as well as public schools, that should deal with the torture at JRC.

PRINCIPLES OF THE AUTISM NATIONAL COMMITTEE

As a member of the Autism National Committee I endorse for all people with autism, pervasive developmental disorders, and related disabilities the development of high-quality community services, including education, residences, jobs/job training programs, and of individualized support services in all locations for both individuals and their family members; of state-of-the-art communication options for all individuals with unique communicative and social needs; of adequate supports to every family to assist them in maintaining their family member with a disability in their home at least throughout the childhood and adolescent years; and the dissemination of available knowledge of those aspects of the disability requiring special support and understanding; the promotion of research to provide parents and professionals with greater insight into the unique needs of individuals with autism and related disabilities; and the use, development, and promotion of positive, respectful approaches for teaching every aspect of life.

Moreover, I oppose the use of institutions to separate people from their communities, and deprive them of dignity, freedom and the level of independence they can achieve in supportive community living; the use of procedures involving pain, humiliation, deprivation, and dangerous drugs as a means to alter and control individual's behavior; the increasing use of bizarre technology to control self-injurious and aggressive behavior; the widespread ignorance of the basic social and communicative needs of people with autism; and the widespread disregard for the individual's unique, basic and human needs. I object to programs which disregard the skills, preferences and basic human needs of the people they serve, and I believe that there is no longer need or any justification for using painful and abusive procedures.

AUTCOM – MEMBERSHIP FORM

Name: _____

Street Address: _____

City: _____ State: _____ Zip Code: _____

Telephone and/or fax (optional) _____

Email _____

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

I am a: _____ Person with autism _____ Parent _____ Friend

_____ Professional (field)

Enclosed is my membership fee of: _____

_____ \$10.00 (person with autism) _____ \$30.00 (regular membership fee)

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

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

I am enclosing an additional \$ _____ to help people on the spectrum attend our conferences

Send the above information and a check in the appropriate amount to

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

WORDS TO REMEMBER

"Can we put aside preconceived notions of what being a "normal" person is, and open hearts and minds to some new possibilities.... It is time to inject fresh ideas and innovations and put the old tired ideas to rest." Anne Carpenter

"Autism's greatest need is getting help with sensory processing so it doesn't feel so intense and so confusing....When someone feels better, then they can act better."

Barbara Moran

"People need to talk softly. One voice at a time works out okay for me. It's easier for me to talk when we talk softly." David Goodman

"I realized that people need to be themselves to go on in life, and need some breathing space to be creative and alive." Xenia Grant

"When you judge me by my muteness and deny me the power of my intellect we all lose.... Hear me now. Ignorance and prejudice still hold too many of us in that silent abyss."

Chammi Rajapatirana

"People with autism are human. Get over it." Robert Cutler

AutCom and Friends



Phil Schwarz (AutCom Board Member) Amanda Baggs (Presenter) and Gail Gillingham (former Board Member and Editor)



President Sandra McClennen reviews books consistent with AutCom principles. Bookstore is run by Mary Schuh of IOD at UNH and Board Member



Louise and David Hackett always on hand to help AutCom in New Hampshire

**"Look ahead. You are not expected to complete the task.
Neither are you permitted to lay it down"**

- The Talmud.

Is it then time for membership renewal or time to join? There's work to be done!

Conferences and More

USD Autism Institute June 28 - June 30

This year the Annual Autism Institute developed by Dr. Anne Donnellan for families, self advocates, students and professionals is featuring work is featuring work shops on Inclusion, Misdiagnoses, FC and Psychotherapy, Sensory & Movement Differences, and Transitions led by Ruth Myers, MD, Martha Leary, Bruce Dake, Sue Moreno, Stephen Hinkle, Nan Negri and others. For more information: www.sandiego.edu/autisminstitute

Autreat in Pennsylvania June 28 - July 2

Autreat will be held on the Bradford Campus of the University of Pittsburg with air-conditioned lodging and open space for comfort and relaxation.

Workshops include Effective Local Advocacy, Counterring Bullying and Cyberbullying, and Technology for Daily Living (being developed at MIT).

For more information:
www.autreat.com/autreat

~ In Memoriam ~ Jackie Richter

lovingly remembered by
Claire Keiser
Jean Goetzman
Anonymous

Sharing Our Wisdom Conference Special

Sharing our Wisdom is AutCom's Collection of stories and issues written by people on the spectrum who are either verbal or FC users will be available at the Conference in Milwaukee only \$5. This is a **one time offer.**

~Always Time to Help~

donations received and
gratefully acknowledged

Pat Edwards

Sarah Stup

Ted Eckberg, MD

Judy Bailey

Patti Meerschaert

John & Cornelia Moisuk

Angela Kionoski

Patty Downey

Donna Gowda

Donations made to help our low income advocates get to our Conferences are always gratefully received and acknowledged.

Dealing with the System: Brookes is publishing Barbara Cutler's book again - for the third time! - in September. Originally titled Unravelling the Special Education Maze, it is written and updated to strengthen parents for the long haul in dealing with education systems, special or otherwise.

AT BOOT CAMP AT UNH

Autism Technology
Summer Camp
July 12 - 16

A week of intensive hands on training in Concord, NH with Credits for Staff Development and for AT Provider CEUs to meet RESNA Standards.

More information at
603.228.2084
or Contact: iod@unh.edu

"Everybody has power.
you just have to use it"
- Granny D

"Theory determines what
you see"
- Marty Gross, Biologist

"The absence of evidence is
not evidence of absence"
- Anonymous

Institute on Disability
University of New Hampshire
12th Annual

Autism Summer Institute
A NEW View of Students with ASD:
Implications for Inclusive Education
August 9-12, 2010
Crowne Plaza, Nashua, NH

The Conference presents 6 Keynote speakers: Jeff Strully, Ari Ne'eman, Cheryl Jorgensen, Judy Endow, Larry Bissonnette and Tracy Thresher who will focus on Neurodiversity, Civil rights, Changing Perspectives, Communication including Facilitated Communication, Assistive Technology, Sensory Issues and Friendships, etc.

Breakout sessions will provide practical strategies to support individuals with ASD, the support people who serve them.

All participants will receive Certificates of Participation, which qualify ASI attendees for 25 Staff Development Hours.

Special Hotel rates at the Crowne Plaza are available through July 9.

For more information, phone: 603.228.2084 or
Website: www.iod.unh.edu/asi.html

"The inclusion of all students is a right and not a privilege to be earned. We believe that inclusive education is a matter of social justice and not clinical debate....We believe that every child (even those with the most severe reputations) can contribute to the real life of the school.....We believe all students can be taught without hurting them. No child should be subjected to physical pain, humiliation or threats.....Full inclusion is a true option with all necessary supports and training to insure appropriate and meaningful education."

AutCom Position on Education. 1991

AutCom (Autism National Committee) 2010 Annual Conference

COMMUNICATION, COMPETENCE, COMMUNITY: NOTHING ABOUT US WITHOUT US!

October 15th & 16th, Wyndham Milwaukee Airport Hotel

Make your hotel reservation - (800) 558-3862 - Ask for the AutCom conference reduced rate.

Co-Sponsored by the Autism Society of Wisconsin

Attention! GF/CF food available –see box at bottom of page to order

Entire Conference (includes breakfasts, lunches & Friday dinner/program)

Individuals with autism: Number of participants _____ x \$110 = \$ _____

Family members/support/students: Number of participants _____ x \$190 = \$ _____

Professionals: Number of participants _____ x \$280 = \$ _____

Friday Day Session Only (includes breakfast & lunch)

Individuals with Autism: Number of participants _____ x \$ 60 = \$ _____

Family members/support/students: Number of participants _____ x \$100 = \$ _____

Professionals: Number of participants _____ x \$155 = \$ _____

Friday Dinner and Program Only (in addition to single day sessions)

Number of participants _____ x \$ 35 = \$ _____

Saturday Day Session Only (includes breakfast & lunch)

Individuals with autism: Number of participants _____ x \$ 60 = \$ _____

Family members/support/students: Number of participants _____ x \$100 = \$ _____

Professionals: Number of participants _____ x \$155 = \$ _____

Donation to Support the Attendance of Individuals on the Autism Spectrum: \$ _____

Total Registration Fee & Donation: \$ _____ **(No cancellation refunds after October 8th)**

Select method of payment: Check #: _____ Purchase Order #: _____

Checks made payable to ASW (Autism Society of Wisconsin) (enclose copy of purchase order)

Visa/MasterCard/Discover #: ___/___/___ - ___/___/___ - ___/___/___ - ___/___/___ Exp. Date: ___/___

Name on card (Please print)

Signature

Name/Names: _____

Address: _____ City: _____

State: _____ Zip: _____ Phone: _____

E-Mail address (required for confirmation) _____

Make check payable to ASW (Autism Society of Wisconsin) and mail conference registration, with payment to:

**Autism Society of Wisconsin, P.O. Box 165,
Two Rivers, WI 54241**

Or fax to (888) 836-4082.

Questions: email jpribek@asw4autism.org

Please circle special requests for meals:

Number requested

Gluten Free _____

Casein Free _____

Gluten Free/Casein Free _____

Vegetarian _____

THE COMMUNICATOR is a publication of the Autism National Committee, Inc., a 501 (c) (3) charitable organization founded in 1990 to protect and advance the civil rights of people with Autism/Pervasive Developmental Disorder and related disorders of communication and behavior. Contributions of articles, information and letters are welcomed. The Communicator does not carry advertising or fund raising announcements, and we reserve the right to edit all submissions. Your comments are actively sought. Send them to Doug McClennen, 619 N. Sheldon Rd., Plymouth, MI 48170 - or email him at: dmc@umich.edu. THE COMMUNICATOR may be copied in its entirety or individual articles reprinted without permission except when otherwise noted. Please credit them to the Autism National Committee.

AutCom Officers

Sandra McClennen, Ph.D., President
Jenn Seybert, B.A., Vice-President
Jim Butler, Secretary
Anne Bakeman, Treasurer
Anne Carpenter, M.S., Past-President

The COMMUNICATOR Committee
Barbara Cutler, Ed.D.
Rob Cutler
Doug & Sandra McClennen

Autism National Committee

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



AutCom and ADA Celebrate 20 Years



AutCom Conference Information Inside