



Volume 15, No. 4 - Fall, 2006

THE COMMUNICATOR

A Publication of the Autism National Committee



The 2006 AutCom Conference in Nashua, NH

President's Message

Anne Carpenter

In early September of this year, I got on a plane for another trip to Nashua, NH, for the 2006 AutCom Conference, once again feeling that wonderful feeling of anticipation and excitement that I always feel when taking a trip and attending a conference. When I arrived at the Crowne Plaza, I felt so glad to have come to a place that felt like home and to be with a wonderful group of people. The warm glow continue as I participated on the Sibling Panel with my oldest sister, Kit, as she talked about her perspective on having grown up with me and the loving relationship we continue to have, despite us living so far away from each other.

On Saturday morning, I gave a tearful, heartfelt President's address on the passing of our beloved Ralph Maurer, and, as I spoke, I once again felt deep regret at this tremendous loss and how we had our work cut out for us, as the public attitude toward Autism Spectrum Disorder has become more negative and "cure" oriented. Excited as I was to be at the conference, I felt this heavy pall of sadness as this was a huge gap that couldn't be filled.

I listened to Morton Gernsbacher's speech transfixed, as she discussed the "epidemic" of autism and how the greater awareness of autism and the broadened definition of autism, to include Asperger syndrome and PDD, was a contributing factor to the increased number of children and adults on the



Anne Carpenter, President, and her sister, Kim

autism spectrum. My only concern was that she didn't mention vaccines as a possible causative factor, but I also felt a sense of relief, being a "Rubella baby" when I was born, because there was no MMR vaccine in the 1950's.

The morning breakout session that I attended was the one by Wade Hitzing on positive behavioral supports. He talked about a young woman in a sheltered workshop who engaged in challenging behaviors that I recognized as her wish to communicate her strong desire to get out of doing boring, meaningless work that was not commensurate with her strengths and interests. This resonated so much with me, because I had done that sort of thing when I was in

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sheltered workshops, to get out of doing something that I just didn't want to do. This included using the bathroom too often, shifting my position in my seat, and slowing down in my productivity. While there was little that was new in his presentation, it was very important and very much to the point.

But in the afternoon, I just lit up like a light bulb when I heard Dr. Paula Kluth discuss "**The Tipping Point**," Malcolm Gladwell's bestselling book, which I suddenly deeply regretted not having read, because she discussed the book's main points in the context of changing how autism was viewed and really making facilitated communication acceptable once again and making full inclusion a common practice, rather than having it only done sporadically, as is currently the case. She said that one must create connections with many different people and that one individual can be a "tipping point." One example of a tipping point for FC was the emphasis on personal stories and testimonials of successful communication with FC, rather than the reliance on validation studies which gave FC a black eye in the late 1990's and caused many professionals to discredit the technique on a wholesale basis, without giving individuals a real chance to use it to their maximum benefit.

Kluth also talked about creating an "epidemic of inclusion." This would allow more children to see peers on the autism spectrum so there would be less fear and negativity and greater understanding, and children with ASD would benefit as well. Kluth's presentation was the highlight of the conference for me, but I really enjoyed the small breakout session where other people with autism talked about supports and what helped and what didn't. Through that, I met people who had wonderful ideas that they could express because they had the opportunity to communicate them through augmentative communication, whereas they would not have gotten that opportunity anywhere else.

And of course, I had The Last Word, along with other people on the spectrum who had been at the conference, and we all agreed that it was one of the best AutCom conferences EVER. After the conference ended, I still felt that warm glow, even as Kit left to go back home, and as I had dinner, went to bed and presided over the Board meeting Sunday morning. The warm glow persisted as the meeting proceeded smoothly and as I headed back home to Ann Arbor. Once again, I felt so gratified to be President of an excellent, high-minded organization.

2006 Conference Highlights

Gail Gillingham

September 8th and 9th found members of the Autism National Committee and other interested people converging on the Crown Plaza Hotel in Nashua, New Hampshire, for our annual conference. This year we focused on the theme, "**Real Supports for People on the Autism Spectrum.**" The conference was dedicated to the memory of Dr. Ralph Maurer. We were very pleased to have a number of his family members in attendance.

AutCom conferences have offered an uplifting experience for everyone who attends, and this year was no different. Family members, professionals and individuals on the spectrum gathered together to share their wisdom and to strengthen relationships that continue across the miles long after the weekend is over. This newsletter is a tribute to the conference, containing photos, presentations, and synopses.

One of the best parts of attending an AutCom conference is being allowed to be oneself. As we listened to the speakers, it can be hard to contain oneself as we want to add our own thoughts to the discussion. Barbara Moran spoke for a lot of us when she said, "I'm sure that at Menninger's (the institution she was in as a child) they may have thought I had 'penis envy' (a Freudian concept), but I didn't. I did have 'status envy,' 'wallet envy,' 'freedom envy' and 'travel envy.' Right now I have 'microphone envy.'" As with everything else, we find adaptations that will work in the moment. Writing our comments to each other either on paper or keyboards allowed us to share with others nearby without distracting the speakers too much.

Our appreciation goes out to the conference committee: Barbara Cutler (chair), Anne & Paul Bakeman, Larry Bissonnette, Pascal Cheng, Rob Cutler, Jean Dalton, Rena Gans, Louise & David Hackett, Alan Kurtz, Zach Rossetti and Mary Schuh - all of whom worked hard to pull the weekend together.

As the conference comes to a close, those on the spectrum are given the opportunity to tell us how we have done in "**The Last Word.**"

Rob Cutler summed up (next page) with a reminder that it is the daily life of each person that is most important, not just one weekend. We left prepared to carry on the work we started here in our own homes and communities.

2006 Conference Highlights - continued

I AM A GOOD MAN. I THINK THAT THE GOOD WORK WE DO IS JUST A BEGINNING. WE HAVE SO MUCH MORE TO DO, NOT HERE BUT OUT IN THE WORLD, SPREADING THE WORD. PHIL IS RIGHT. WE NEED TO JOIN TOGETHER WITH OTHER CIVIL RIGHTS GROUPS. WE HAVE TOO LONG THOUGHT OF OUR WORK AS A SEPARATE PIECE OF THE PIE. WE ARE ONE PIE - THE HUMAN PIE. JOIN ME TO SERVE IT TO THE WORLD. WHERE DO WE GO WHEN WE LEAVE HERE? I DON'T WANT CREATING ARTIFICIAL SITUATIONS WHERE WE APPEAR TO PASS BUT REAL SITUATIONS WHERE WE ARE ACKNOWLEDGED FOR THE GIFTS WE HAVE TO OFFER THE WANTING WORLD. LEAVE THIS PLACE AND FIND YOUR VOICE. DON'T BE AFRAID. WE ALL NEED TO TELL OUR STORIES. THANK YOU ALL. I LOVE THIS WORK AT CONFERENCES BUT NOT AS MUCH AS MY TEACHING JOB. IT IS THERE THAT I AM NEEDED. IT IS AT THAT PLACE WHERE MY LIFE HAS MEANING. YES.

For next year we are planning our first international conference for Edmonton, Alberta, Canada. Mark your calendar for the weekend of September 27th-29th (a longer conference) and be sure to get your passport in time to join us.



Barbara Cutler presenting AutCom's appreciation to Ralph Maurer's family

The Autism National Committee thanks the following Organizational Sponsors and Individual Contributors for their generous support of the 2006 Conference, "Real Supports for People with Autism," which was held on September 8-9 at the Crowne Plaza Hotel, Nashua, NH:

The Northeast Regional Conference on Autism
 The Institute on Disability, University of New Hampshire
 The Center on Disability and Community Inclusion, University of Vermont
 The Facilitated Communication Institute, Syracuse University
 The Massachusetts Developmental Disabilities Council
 The Vermont Developmental Disabilities Council
 The Autism Society of Michigan
 Jay Nolan Community Services
 Virginia Maurer (in memory of Ralph Maurer, M.D.)
 Marna Ares
 Paul & Anne Bakeman
 Larry Bissonnette
 Char Brandl
 Jim Butler-Arkow
 Pam & John Cooper
 Lois Cote
 Barbara Cutler
 Jean Dalton
 Pat Edwards
 Rena Gans
 Morton Ann Gernsbacher

Gail Gillingham
 Debbie Gilmer
 Louise & David Hackett
 Paula Kluth
 Lisa Lieberman
 Sandi & Doug McClennen
 Mary Nazzaro
 Judy Riggs
 Zach Rossetti & Friends
 Phil Schwarz
 Jeff Strully
 Elaine Sullivan
 Michael & Angelina Umali
 Margo Williams
 Martha Ziegler

Thanks to our AutCom Conference Speakers



Larry Bissonette (above),
Anne & Kit Carpenter (photo on first page):
"Relationships: Families, friends and lovers"



Morton Ann Gernsbacher, Ph.D. (right)
"The science of autism: Beyond the myths and misconceptions"



Rob Cutler (above) and Michael Dowling
"The person with autism as mentor"
(See report and another photo on page 12)



Lisa Lieberman, MSW, LCSW
"Challenges families face in finding and working with staff in their homes"



Pascal Cravedi-Cheng (at the keyboard):
"Growing your skills with facilitated communication"

Thanks to our AutCom Conference Speakers



Linda Rammler, PhD:
"MACS attack: Understanding the impact of motor, anxiety, communication and sensory challenges in autism"



Paula Kluth, Ph.D. (with Nicolette)
"The 'tipping point' and how we can use it to articulate our mission"



Dr. Tom Larson
"Chiropractic craniopathy in autism"



Wade Hitzing, Ph.D.
"Behavioral issues in autism"



"Real Supports: What helps, what doesn't"
Speakers:
Barbara Moran (above)
Amanda Baggs (article and photo on page 6)
Phil Schwarz (report page 9 and photo page 14)
Tracy Thresher (article and photo on page 10)

Amanda Baggs - Real Supports: What works, what doesn't

Kathleen Seidel read this speech while I was lying on the floor (right) mostly watching my hands flutter, so I was right about the unpredictability factor.

Introduction

A bit about my supports: I'm a veteran of Californian institutions and their segregated schools. I got supported living services in California, and I now get something similar in Vermont. I'm part of a pilot program in Vermont that uses electronic surveillance at night instead of roommates for people with severe disabilities.

I'll talk about the mechanics of support, and then I'll talk about attitudes. I'll assume since it's AutCom we all know that institutions and aversives are bad, so I won't dwell on that. Instead I'll talk about what can crop up even with these values and what to do about it.

The Adventure of Autism

I'm writing in the shower. Someone's washing my body, and my mind is checked out, busy writing my talk. My hands will type it onto a computer later.

By the time you hear it, I don't know how I'll be. I don't know whether I'll type fast and without support, or painstakingly slow with physical support, or not at all. I don't know if I will be able to use standard English, or my more natural language of condensed metaphor, or nothing. I don't know if I will be able to understand questions, or what an audience is, or any part of the room beyond patterns of sensation. This is part of the adventure of being autistic.

Flexibility: Storks

Storks can't fly far under their own wingpower so must catch air currents called thermals. As an autistic person, I have to catch thermals in my head: Perception, movement, symbol, language, pattern, contemplation. These are not reliable.

This ever-shifting maze of thermals means that what we can and can't do is unpredictable. Service systems are made for people whose skills remain constant. They need to become more flexible in order to allow for lives in which the only constant is fluctuation. I need a different level of support every day, sometimes every hour. We need more than one-size-fits-all formulas.



One Size Does Not Fit All

The traditional response to a person with a severe disability is to give them a roommate. I've had a migraine every day for the past few years. I need time every day with no stimulation at all, not even someone's presence. I also have a movement disorder that makes it harder to move, the more stimulation I encounter. Living with someone means that I spend all my time unable to purposefully move, occasionally screaming or vomiting or hitting myself in the head. It's about health, not just preference. I wonder how many other people are in that situation which is wrongly considered "just part of their disability" rather than a reaction to part of the environment that could be modified.

I'm part of a pilot program in which at night they turn sensors on. If certain things happen in the house, they listen in and then come over to my house. This means I don't have to have someone overnight in order to be safe in my house.

I can't get all my medications because only roommates are allowed to administer some of them, so I have untreated infections and other medical problems.

We need creative things like paid neighbors and electronic surveillance for people who don't want or can't live with a roommate. Right now, many people have an unacceptable choice between neglect and incapacitation.

Unusual Supports

This is Fey. She is my cat, and my longest-term, best trained and most reliable facilitator. I am not joking. She walks up and down my body, nudges and nips, and figures out how to help me

Amanda Baggs - Real Supports: What works, what doesn't



Amanda and her cat, Fey

get moving. Unlike when I use human facilitators, nobody ever claims that Fey is the real author of my work.

Unfortunately, it's hard to train staff to facilitate. They don't all have the knack that Fey does. I use physical facilitation for many movements beyond communication. Right now the only nearby human who knows how is my friend Laura despite my agency's FC trainer being session D2 today. Trapping autistic people by not training staff needs to stop being acceptable.

Creativity is also important: Who'd have seen a cat as a facilitator? Fey did.

Nobody ever gave me a list of what supports are out there. That means there's probably all kinds of things I don't know about. We need to know what's out there. People need to tell us.

People need to listen to us. I can't count the number of times I've either been taught something I already know or else had something I desperately needed overlooked. When I object, people say they know best.

This is why I dread the utterly dehumanizing process known as the "skills assessment," wherein someone squashes my complex life onto a piece of paper. Inevitably, they either focus on my writing skill and forget everything else, or they assess

my life skills and say that I'm too low-functioning to know what's good for me. Did you know that I scored as low as possible on a test of communication last year?

This is a good time to talk about attitude rather than mechanics.

Do-Gooders: An Introduction

"Good job!"
High-pitched screeching voice
I cover my ears to block out 'praise'
And look for a way out

A cat contented on the floor
Is grabbed up into 'loving' arms
That squeeze her as a voice squeaks noises
Meaningless and loud

"I am good with autistic people,"
The screech confides to a friend.
"I am good with cats," it brags.
The cat and I hide under the bed.

Do-Gooders: A definition

My statements about do-gooders are not meant to put people down, but rather to point out a common dead end and how to get out of it.

Frequently, in the DD field, I see a person across the room with a "saintly" glow about them. My first reaction is to make sure that they won't see me or speak to me if I can help it. But sometimes there's no escape.

Unfortunately, some people are attracted to that glow. They don't know it is the fools-gold glow of a misdirected ego. Truly selfless people do not poke out so far beyond their bodies or run around announcing themselves like that. Truly selfless people are not so poised and perfect and worrying what others think about them. Truly selfless people are amazing when you meet them, but they are more down-to-earth and far rarer than your average garden-variety do-gooder. They don't tend to announce themselves.

A do-gooder confuses doing the right thing with feeling good about themselves, a selfish pursuit of selflessness. Do-gooders flock to the helping professions because they are good places to feel like

(continued on next page)

Amanda Baggs - Real Supports: What works, what doesn't

you're helping even if you're not. Even people who are not yet do-gooders can get turned into them by exposure to do-gooders held up as shining examples in the field. Fortunately it's reversible with effort.

How to Resist Do-Gooderism

That warm fuzzy satisfied feeling you feel when you think you've helped people? Ignore it. It's like a drug. You can destroy lives pursuing that feeling and not even notice.

Find out what your clients need and want, and of equal importance, what we don't need and don't want. Listen to us when we like something and when we don't like something. Don't take correction as a sign that you're evil; take it as a sign that you're learning.

Don't make a big show of how much you're learning from us, either. Bowing at our feet is usually a sneaky way of towering above us—it's false humility. Real humility means neither shrinking nor puffing yourself up. Meet us as genuine equals, neither put on a pedestal nor driven into the ground.

Also avoid putting our words and deeds on a pedestal. Dave Hingsburger once said that anyone who likes every person with a disability is bigoted, unable to see individual differences. Anyone who likes every word we say or everything we do is incapable of differentiating between one thing we say or do and another. When we're your equals, you agree and disagree and evaluate and think, not just heap extravagant praise on us.

Never forget that even if we're technically your boss, you have more power over us than we do over you. You can get another job. We will always need staff, sometimes for things as basic as communication or freedom of movement.

Think about things in that context. Expecting or demanding gratitude is laden with power problems. Imagine having to appear cheerful and grateful, no matter your mood, to get food or be allowed to communicate. Until this power situation changes, you won't be able to trust that the praise and thanks we offer you is not really terror in disguise.

The book **"Power Tools"** by Dave Hingsburger is a great little book about power and control in the human services industry. I'd recommend finding a copy. Many of his other books are worth reading, too. He himself is a recovered do-gooder and can help other do-gooders in their own recovery.

If you start to recover from do-gooderism, you'll find the rewards are far greater than that

warm fuzzy feeling I mentioned. Just as drugs offer only a counterfeit happiness, warm fuzzy feelings only prop up the ego that blocks you from both real happiness and really doing the right thing.

Also, everyone is exposed to and affected by disability prejudice. The following are examples from my own life of situations where people can take their prejudice to work with them.

Not What It Seems: Shame

I appear to have a genetic syndrome that makes me look a bit different than usual and like I'm a blood relative of other people with the syndrome. I used to hate my joined eyebrows and all the other things that make my appearance a bit different. Doctors and schoolchildren alike told me this appearance was ugly, diseased, and misshapen. I believed them.

Some people said my feelings were natural. They offered surgery and hair removal. Other people said, "Hold on here. You're not ugly." They showed me paintings by Frida Kahlo who had eyebrows a little like mine and exaggerated them in paintings.

When we hate our bodies, our supporters need to learn about disability shame and know it is like a girl who vomits after meals to try to be thin. When people treat our shame as natural, they are doing the same as the magazines who only print skinny supermodels.

I am strong enough now that when someone calls me names like retard, I can laugh inside and type to them, "And proud of it!" The people who support us can help us be rid of our shame but can also make it worse.

Not What It Seems: Cuteness

There's something that happens when I am treated like a child. A routine snaps on in my head. I giggle a certain way, I react a certain way: Cute, utterly harmless. I may be too old for physical cuteness, but I can have a cute attitude.

Some staff mistake this for connecting to me. They do the right triggers, I giggle, and they think they've made a connection to me. All they've made a connection to is internalized disability oppression: "Be cute and people will protect you. Be cute and people won't hurt you."

People can even believe that when I fight this reaction, there's something wrong with me, that I'm getting a bad attitude. Really, I'm just trying to act like my personality, not a wind-up doll. Many other women will know what I am talking about when I say

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that assertive women can get called bitches for not being deliberately cute and non-threatening. The same happens with us. Please make it easy for us to be three-dimensional.

Not What It Seems: Dividing

Some people say I am a shell with no person inside. They see a tiny part of my body but refuse my mind. Some people say they can't understand why anyone thinks I look unusual. They see a tiny part of my mind but refuse my body.

My mind and my body are intertwined. People are only masking their own prejudice by pretending one or the other isn't there. My looks and my writing are part of the same person. Chopping me into manageable bits will never be a compliment. I do not want to be forever chopped in half for people to be comfortable in my presence. I am a whole person. Take a good look: This shifting soul and this shifting body are me.

Phil Schwarz - Real Supports: What works, what doesn't

A report on his presentation

Phil Schwarz, our newest Board member, was asked to represent the Asperger part of the spectrum on the panel of presenters on real supports. He reminded us that a spectrum cannot be one dimensional but is multidimensional, with many areas of ability/disability found within the spectrum, and that these abilities are more orthogonal than "conventional wisdom" would have us believe.

Phil outlined a number of abilities used by "conventional wisdom" to measure how people function. These include having functional language and literacy, the ability to manage self-care, to maintain or co-maintain a household, to hold a job, to pursue a formal education and to function as a citizen and consumer. There is a wide variability in all of these categories, not only in the way they are manifested in each individual but also in the way that they fluctuate over time and in different situations. "Conventional wisdom" has a tendency to measure them concretely and put them in a hierarchy which adversely affects how support is offered and delivered. Real Supports are those that are flexible according to individual needs and individual situations in the moment.

After discussing the eight categories in detail, Phil went on to outline how real support must go on beyond these nominal categories. He stressed the importance of prompting, check-in, feedback, coaching, mentoring, interpreting, and breaking down problems into stepwise, solvable categories. He also stressed how important it is to recognize that support may not need to be continuous but may be needed intermittently.

The model of disability as constant and permanent may appear to be useful when one considers disability law and economics but presents a barrier when one is looking for real supports. Variable degrees of stress from external factors over time contribute to the variable degrees of disability over time. Skill acquisition over time needs to be accommodated and should not jeopardize unrelated entitlements and arrangements-in-place.

Other factors that are rarely considered are the attitudinal concerns for providers, such as respect. He reminded us that no type of disability makes one less of a person. We must make the effort to identify and actively counteract societal devaluation of some types of disability. We must understand the non-universality of the majority's ways. They are not always the right way. Just because something works for most of us does not mean that it is the only way things can be done. We must presume competence and recognize that there is a huge difference between knowing how and not having a body that will follow through on what we know. We need to know how to tell the difference in these circumstances and be able to find and provide ways to adapt.

Phil concluded with the reminder that we must be aware of the power imbalance that people on the autism spectrum face each day. Providers are there because they can do something that the client cannot do and needs to have done. This need-beyond accessibility generates the power imbalance. It is imperative that we wield this power very carefully.

Tracy Thresher - Real Supports: What works, what doesn't "Possibilities"

The speaking is what I want to focus on. What could I do to let the rest of the world know how badly I want to speak? Can they hear it in my voice or see it in my right hand typing the letters or words? Can they feel it in each word that is read silently? Past the silence into the world of speech I go, wishing my right to softly be in this real world of speech. That is my greatest challenge, to speak my words and type what I want to speak.

I am Tracy Thresher and I want to share my thoughts on using facilitated communication (FC) and having a voice. I have been using FC for about 16 years now. Not being able to express myself was like being in a world of silence. I couldn't tell people what I liked and didn't like. People thought I was retarded and that I didn't understand what was being said to me. It was frustrating and made me angry, so I withdrew. The experience of the world looks different from my experience. Most people take their ability to talk for granted, and I take my inability to talk quite seriously. I live with it every day. It is always there each time someone wants to read my thoughts.

The impact of learning to speak up and have a voice has been quite meaningful for me. I have typed life goals and dreams that have actually come true. One dream of mine was to go to church and be baptized. I told my mother this, and it happened. I have been able to meet with my Pastor and discuss God and the Bible because religion is important to me. I am learning to do the things I want to—teaching others about autism and FC and movement difference. These are things I have wanted to do, and now they are happening. I have spoken about these things I wanted for my life and some have come true. This would never have happened without FC.

One of the barriers to speaking and being heard has been learning to work with facilitators; they don't always know what to do and have to be told little bits of information at a time. It is also difficult to deal with staff turnover. When staff leave, I have to start all over again. It is hard to deal with someone who isn't familiar with me or with FC or me with them. The problem of working with new facilitators is looking for the words and they look right back at you, but the words are stuck and don't come out. What does come out are typed preservations and echoed phrases. Does anyone



Tracy Thresher (right) with Harvey Lavoy

know what that feels like? That is anxiety at it's highest! The learning is damn worthwhile when I can let someone know what I am thinking. I teach others about keeping with me when I type something. I want others to know that not being able to talk doesn't mean there's a lack of understanding or that the person doesn't want to share what they are thinking. Letting people know what my dreams, wishes and desires are has helped me manage my anxiety. Not being able to speak doesn't take away the desire and need to have respect and the attention of others.

Wars of Autism

I want to type about wars of Autism, movement and speech. With Autism my speech is unreliable and the words are stuck in my head fighting to come out. With typing I am able to get the words out and let people know what I am thinking and feeling. Doing facilitation properly requires patience, understanding and training from top notched facilitators like Harvey Lavoy. With that people can know the real me.

Volume of communication is hearing my voice and taking the time to type and talk with me. Wanting to type is one thing, having people to talk to is another. While in Whittier, CA, I had the chance to communicate with several people who listened to me and knew I would respond in my own way by typing. So much of the communication process depends on

Tracy Thresher - Real Supports: What works, what doesn't "Possibilities"

people taking the time to listen and to ask enticing questions. With time and patience I can have some really thoughtful conversations. What works for me is communicating with thinking, patient people that understand my Autism and work through the problems with anxiety and impulsive movement problems and focus on thoughtful communication.

Want to treat people to my interior thinking. Sometimes I think wanting to say the words is what will convince others of how I really do understand. But of course I can't say the words and passively stand alone hoping the person that is trying to communicate with me will see that I am wanting social contact, relationship and conversation. With a respectful favorite facilitator I can experience those things. Without people satisfying my meaningful typing conversations, I am at risk of being labeled as not understanding, not wanting to communicate, or wanting to do something else.

What my experience has been with trying to communicate before FC was frustration, erratic behavioral times to get my way, and helplessness. Now when typing I can self-express and connect with others in a way that wasn't possible.

Possibilities.....please take time to hear my voice. Now good proper support from my case manager

Rachel and daily proper support from Tristan and with Harvey's guidance, I am getting real possibilities in my life. The main focus has been to train others. I wanted to be in the limelight doing training for so long. Syracuse, California, Michigan and Illinois training have given my dream the opportunity to present and show people how smart an autistic man is without speech. The really wonderful Marilyn Chadwick and Mayer Shevin have helped make this possible. Meeting Jamie and Sheree Burke was a tremendous experience. I watched Jamie speak his typed words out loud and was so utterly eager to do that myself that I jumped out of my silence and read the first part of a speech I had typed for a Communication Conference in Vermont. With that experience I was on my way out of silence, using a voice that went under-utilized for all of my life. This is bringing a smile to my face as I type it. How heartwarming for a silent autistic man to gain a voice.

Yes, I want to type to fine people out there to hear the sound I make when reading my typed words to you. Do you hear the possibilities?

Tracy Thresher, Trainer and self-advocate
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Scenes from the Conference



The Person with Autism as Mentor

A report on the presentation



Left to right: Akeem Evans, Rob Cutler, Michael Dowling, Ryan Evans, Amanda Sweeney, Bo Lembo

Medicine Wheel

Robert Cutler and Michael Dowling shared the spotlight with Odyssey High School students Amanda Sweeney, Akim Evans and Ryan Evans and their teacher Bo Lembo, all of Boston. They worked together to beautify an abandoned patch of land. But, they explained at their session, learning about each other was even more important.

Rob told of his experience with the project:

I love being at the high school. It is a very rewarding job. The first day I was there a young woman came out as disabled by standing and announcing you have a disability so do I. I found out later that she had not spoken in class before that. She, when we were making handmade books, was the only student who could divide one sheet of paper into six equal pieces. Some disability. Not! I can only say that the measured sameness we expect from each of our youths dumbs them down and away from their gifts. We spend the most time mining for the intrinsic value and gifts of each young person before we begin our work.

He then called on each of others, adding more of his perspective:

RYAN, CAN YOU TALK ABOUT FINDING YOUR TRUTH WITH OTHERS WHO DO NOT SHARE IT AND STILL FEELING GOOD? I AM THE HAPPIEST WHEN I HEAR THE STUDENTS SPEAK. RYAN HAS BEEN ONE OF THE BEST TEACHERS OF ACCEPTANCE FOR THE GROUP. WE HAVE SO MUCH TROUBLE WITH DIFFERENCES. RYAN DOES NOT. HE IS ENLIGHTENED. YOU CAN BE TOO IF YOU TAKE THE TROUBLE TO SEE YOURSELVES AND BE A MIRROR FOR OTHERS. HOW DO WE STOP BEING SELF CONSCIOUS AND BECOME SELF AWARE? WE HAVE TO PRACTICE BEING OURSELVES WITHOUT JUDGEMENT. NOT AN EASY TASK.

Each spoke about how the experience changed her/him, particularly by helping them feel included as a part of a community working to accomplish a purpose. Before leaving the conference, the three students each wrote about their experience for this newsletter.

Ryan Evans: Though I still have little knowledge of autism, I will be glad to fight for the misunderstood. For Medicine Wheel, I shall always be more than happy to speak for and support it. That goes for this conference as well.

The Person with Autism as Mentor - continued

Akeem Evans: I really enjoy talking about my experiences with people who have autism. The thing that really touched me when I got to know everybody with autism is this: "People with autism are not different from us and you should be treated equally like us."

Amanda Sweeney: It has been a great experience working with Rob and Medicine Wheel to help spread the word about inclusion and acceptance.

THESE YOUNG PEOPLE ARE MY HEROES. INCLUSION DOES NOT EXIST ANYWHERE TODAY. WE GET CLOSE BUT SOMEONE IS ALMOST ALWAYS LEFT OUT. WE TRY TO TEACH THAT WHAT ONE DOES ON A SMALL SCALE HAS GLOBAL SIGNIFICANCE. WE CAN EACH OF US START EACH DAY WITH THIS IN MIND. IT THEN HAS UNLIMITED POTENTIAL. WHEN ONE LEARNS TO GIVE RESPECT I HAVE TO SAY ONE IS ENLIGHTENED.

After Ryan, Akeem and Amanda spoke, Rob concluded:

Autreat Conference Kathy Grant

'60s in Philadelphia 2006 - Autism Network International (ANI) Conference

I'd never thought I would gain an understanding of a time period in American history by going to an autism conference. My main goals for going to Autreat in Philly this year were these: 1) People have been begging me for ten years to go, and 2) I am one of the founders of Autism Network International (ANI), so it would be nice to be at a conference with an organization that was founded by me, Jim Sinclair and Donna Williams in St. Louis, MO, in February, 1992. I went with my friend Joel from Laramie, WY.

How did I learn about the '60s from this conference? By being among my own people, I realized that I can 'let go' and just be myself. I didn't have to keep under wraps some parts of myself simply because people wouldn't understand them. I could totally be myself and realize that I was "groovin'." It is nice to be among people who totally understand you. Also, it was a communal experience in that we just were. In the late '60s, many hippies had Be Ins where they could just be themselves. (I am purposefully excluding the drugs and sex.) I realized at this conference that the '50s was the decade of McCarthyism, conformity, Ike, and the start of the Civil Rights movement. In the 50s, people like me were not seen or heard. We weren't even in the back of the bus. We were hidden in institutions and then not thought about. And people think the '50s were great? Great for those white people who were not different or leftist. On a side note, when I was in Philly, I met a Communist whose parents were harassed during the McCarthy period and even the records were destroyed. But then a few people like Jack Kerouac, some beatniks,

Martin Luther King, and others decided that America is for all the people, not just the privileged few. And then the young people, flamed by the idealism of JFK and the Peace Corps in the early '60s, wanted to make America a better place.

And Autreat taught me that. The young people of the '60s, tired of the hypocrisy of conformity, the lies of Vietnam, and fueled by the idealism of wanting to actually help those who don't share in the American dream, made this country a better place. In fact, without the Civil Rights movement, there would be no disability movement. And not only that, but many of the leaders of the counter-culture of the '60s had neurological differences. Abbie Hoffman was either bi-polar or had depression. I believe that Janis Joplin had undiagnosed Asperger syndrome, that Jim Morrison of the Doors had a different brain chemistry (what, I don't know, I just know that he perceived things differently), plus countless others who perceived things differently and made themselves known and in many ways changed the country for the better.

It was at Autreat that I realized that people need to be themselves to go on in life and need some breathing space to be creative and alive. Also, Autreat was a place where you could ask for help and not be looked down upon. Autreat was a place where you could not worry what others think and just BE. Also, the relaxed pace of the conference helped because the rush, rush, rush of this world is killing people, and we're not even realizing it. And it was in this atmosphere that I realized that this country needed the '60s. People need to be themselves and not always hide who they are, and to me, that is what the '60s taught.

Introducing our Newest Board Member

Phil Schwarz, 50, has AS, is married to Susan (who is not on the spectrum) and is father of Jeremy, who has autism, and Rachel, who is in the broader phenotype. He is a software engineer by profession.

Phil is vice president of the Asperger's Association of New England and has played an active role in its leadership for many years. He has also been long active with Autism Network International, including the program committee that plans the annual conference/retreat, Autreat. He has been an active participant in the autistic community and the autism self-advocacy movement on the internet. He brings the connections he has made in these capacities and his knowledge of people and resources to the AutCom Board.

His principal goal as a board member is to advance AutCom's visibility and clout by fostering greater connection and cross-pollination between AutCom and other organizations, resources, and people across the autism spectrum who are working toward common goals of human and civil rights and



Phil Schwarz

greater understanding, equity, and parity for people with autism in the larger society. He'd like to broaden the presence and awareness of AutCom in regions of the spectrum in which it has not historically been associated.

Support the Autcom Bookstore!

The AutCom bookstore, which is available online at www.autcom.org, represents one of the most important functions of the organization. In a world full of misunderstanding and misrepresentations concerning autism, the bookstore offers a clear path to what is useful and informative. Every book and pamphlet has been checked against the principles of the Autism National Committee (as stated on the facing page).

Visit the website and check out the selection. Find information about many of your pressing concerns. Tell everyone you can about this resource. It is the best autism-related information available!



Sandi McClennen finds it hard choose, with so much to choose from!

MEMBERSHIP FORM

Because I endorse the principles of the Autism National Committee, I would like to (circle one):

JOIN NOW

RENEW MY MEMBERSHIP

NAME _____

ADDRESS _____

CITY, STATE, ZIP _____

PHONE _____

E-MAIL _____

I AM A (circle): Family member Person with autism Friend Professional (field _____)

Annual membership: \$30.00. Persons with autism: \$10.00. Supporting membership: \$75.00

I am enclosing an extra \$ _____ to speed up the good work.

Make checks payable to Autism National Committee and mail to:

Autism National Committee

Wade Hitzing, Treasurer

1045 Wittman Drive

Fort Myers, FL, 33919

The Autism National Committee is a 501 (c) (3) charitable organization. Your contributions are tax deductible and will be promptly acknowledged for your records

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 appropriate community services, including education, residences, jobs/job training programs, and of individually appropriate and adequate 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 disabled family member 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.

**The Autism National Committee
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Time to Renew or Join Today!

**Annual membership begins in January
(Membership form on page 7)**



THE COMMUNICATOR is a publication of the Autism National Committee, Inc., a 501 (c)(3) charitable organization founded in 1990 to protect and advance the civil rights of people with Autism/Pervasive Developmental Disorder and related disorders of communication and behavior. Contributions of articles, information and letters are welcomed. The Communicator does not carry advertising or fund raising announcements, and we reserve the right to edit all submissions. Your comments are actively sought. Send them to Gail Gillingham at PO Box 11245, Main Post Office, Edmonton, Alberta, T5J 3K5, Canada, or e-mail her at: exgr@telus.net

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