



Volume 18, No. 2 - Summer 2009

# THE COMMUNICATOR

*A Publication of the Autism National Committee*



## 2009 AutCom Conference

September 25 - 26

Nashua, New Hampshire

(Go to pages 14 - 15 for information and registration.)

### Please Help Other Members Attend the 2009 Conference

It has been AutCom's policy to help people on the spectrum attend our conferences so they can share their firsthand knowledge about ASD with each other and the rest of us. This year, the economy causes an even greater need for this support.

Please help by contributing what you can afford.

Mail your contribution to:

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

If you are joining or renewing membership or registering for the conference, add your donation and check the appropriate box on the form. This is an excellent way to advance firsthand knowledge about ASD while helping people who experience it feel valued.

### Show Me The Evidence

*Evidence-Based Practices for Supporting  
Students with ASD in Schools and  
Communities*

August 10-13, 2009

University of New Hampshire Institute on  
Disability in Durham, NH

For more information:

[www.iod.unh.edu/events.html#asi](http://www.iod.unh.edu/events.html#asi)

### Summer Institute 2009

*Facilitated Communications, Inclusion and  
Independence: Crafting a New Narrative*

July 13 -16

Syracuse University, Syracuse, NY

Registration deadline: July 8

(or until program is full)

Questions: (315) 443 - 9379

<http://inclusioninstitute.org/fci>

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

## Abuses Under Congressional Scrutiny

Spurred on by a GAO report, Congressman George Miller (CA) held hearings to further investigate reports of trauma, physical injury and even deaths caused by the pervasive use of restraints in schools and other programs serving children and youth with disabilities. Congressman Miller has said, "It is wholly unacceptable for the egregious abuse of a child to be considered less criminal because it happens in a classroom....Congress must step in and fill the void that has resulted in scars that may never heal for these children and their families who have been victims of this abuse."

There are a number of concerned organizations gathered in the coalition called the National Disability Rights Network which includes the APR AIS network and COPAA (the Council of Parent Attorneys & Advocates) seeking to generate public interest in the deadly use of restraints and to move the government to enact a federal policy to protect children with disabilities. CIBRA has been working for years to bring these issues into the public light. And AutCom was founded on issues of social justice for people with disabilities almost 20 years ago. AutCom further approved the strongest position paper on restraints 10 years ago. It follows this article. No resolution from any organization before or since has come close to the strength and clarity of our position.

Jessica Butler of COPAA will be presenting at our 2009 Conference September 25-26 to bring us up to date on the results and offer future direction.

## AutCom Position on the Use of Restraints

The Autism National Committee condemns the widespread and excessive use of mechanical and physical restraints in restricting the civil and human rights of people with disabilities. We believe that the use of restraints is a failure in treatment.

People who have survived forceful restraint have reported they feared they would die in restraint, and some have died. A number of tragic cases of restraint-related deaths of children and adults have recently made the national news. Estimates of

deaths occurring during or shortly after restraint currently range from 50 to 150 annually. The actual magnitude of such deaths is poorly tracked and subject to under reporting, a fact recently stated by a federal Department of Health and Human Services spokesperson.

Many have reported that they now live with fear and flashbacks that involve a sudden, involuntary re-living of this emotional and physically traumatic experience. Post-traumatic stress disorder is increasingly being diagnosed among persons who have been subjected to the systematic use of restraints.

It is clear that individuals sometimes desperate efforts to communicate are ignored while staff force compliance for oftentimes trivial reasons; that the cumulative effects of repeated restraint can lead to diminished self-image and negative attitudes; and that when restraint is used, struggle is provoked and this natural response increases the danger of physical injury.

In our experiences as professionals, parents, and individuals with autism, we have witnessed too many times the horror and injury done to our citizens with autism. We are weary of seeing our people become victims.

Although any one of us, disabled or not, may at some point in our lives need to be restrained on an emergency basis, that should only occur when there is substantial threat of injury to self and others. Behavioral restraints are neither treatment nor education. They are merely procedures or methods that restrict freedom of choice and adversely affect the human development of people with disabilities. The use of restraints should be considered a failure in treatment. We totally condemn the use of behavioral restraints.

We call on national and state agencies to investigate the widespread mistreatment of people with disabilities through the use of restraints.

We call on Congress and state legislatures to pass legislation to protect people with disabilities; to limit the use of restraints on children and adults with disabilities to brief, emergency situations involving serious threat of injury to the person with disabilities or to others; to require immediate reporting of these incidents; to require thorough investigations of the circumstances that lead to the incident; and to require the development of supports and accommodations to prevent future incidents.

## President's Letter

by Sharisa Joy Kochmeister

I have started a new magazine for autism with a positive, hopeful spin... called "The Voices and Choices of Autism". If you're interested in receiving/writing/creating art, please contact me at [sharisajoy@yahoo.com](mailto:sharisajoy@yahoo.com). Subscription is free, and the first issue is available. Authors and advisors include people on and off the spectrum.

Our mission is to expand understanding and acceptance of people on the spectrum and the idea that this isn't a disease to be cured but rather a way of living and being that should be understood and supported as needed, with people being supported as active participants in the support. It's our goal to give those on the spectrum and those who care and advocate for them an open, widely read forum in which to share, learn and express in a positive, open, hopeful manner. Tell me what you want future issues to include!

I'm also very much looking forward to the 2009 AutComconference where I will be doing a presentation, "When the Wires Misfire: Battling and Overcoming the Mind-Body Disconnection."

My thoughts are with you all as I endeavor to feel better, create more, and spread positive thoughts and words and feelings!

## Society, Behavior and "Diversity"

(A Brief Rant by a Frustrated Adult -  
Seeing "Red")  
by Sharisa Joy

In the larger scheme of things, I have now lived more than half my life in the world of communicators. October 10, 2008, marked my re-birthday, the day I began communicating via typing at age 13 in 1991. Thirteen years of tantrums having been my only real way to communicate frustration had shaped me into a teenager who people feared. Did they know that I also feared myself? My screaming hurt my own ears, my wailing was so infantile, my inability to make my needs known was so frustrating, and my behavior was extremely self-destructive as well as socially disruptive and destructive. I was a force to be reckoned with, much stronger than I appeared at 69 pounds and 4 feet 9 inches. When adrenaline flowed, I seemingly had the strength of the "Incredible

Hulk" without his ability to <choke> control his rage. While I had never truly hurt anyone, their fear was palpable and it fueled my anger against my plight.

These days, as a calm and rational <rolling eyes and looking innocent> adult, I have managed not to have tantrums. While the occasional rage (the psychiatrist prefers to call them "frustration") attacks I have now are far worse than any tantrum, I am learning to control them and not allow them to control me.

I am, after all, expected (and expect myself) to act like a neurotypical adult (note the word "act" AND all of its possible meanings). Usually, I manage to pull it off in a way that could win an Oscar. There are times, nevertheless, when my rage gets the better of me, when my frustration and anxiety fuel my actions, when my dyspraxia fails to stay under wraps, when I flail and wail and attack!

Afterwards, of course, I feel contrite; but during an attack there are feelings that defy description, emotions that defy definition, and anger that defies explanation and understanding. I am a thermonuclear meltdown personified. I have seen myself in mirrors when this happens, and I look as frightening and frightened as I feel.

What causes my rage (frustration)? In general, as well as I am able to pinpoint it, it is mostly related to feeling negated. When people ignore me, put me down, deny the reality of who I am, the need I have for understanding, the fear I have of losing the ability to type and once again becoming non-communicative, I quite clearly "lose it". While I can't say exactly what this "it" is that I "lose," its sudden disappearance threatens my humanity and my sanity, and I stop being the me I have chosen to be and revert/regress to something far less that I have trouble even recognizing.

When I witness discrimination based on difference(s), I take personal umbrage and there is no flight but plenty of fight within me. When I hear people saying people with autism need to be "cured," I refuse to feel like some kind of "untreated meat" and I react. I say "cure ham, not people!" I don't have a disease - I have a set of disabilities that cause unease - especially for me! People may not like the way I react; heck, I don't even like the way I react; but it's part of who and what I am and the essence of Sharisa is something that cannot, will not, should not be changed - and certainly not something to "cure"! Treat what ails me, by all means, but don't

Continued on next page

Sharisa Joy continued

fail me by denying who I am!

So please, take your talk of curing and defeating autism and do not foist it upon me or anyone who feels autism is not a disease. Additionally, please accept and respect us for who and what we are, for what our autism has helped us be, for the valued members of society and teachers of the neurotypicals we long to and deserve to be! Enough said for now - but feel free to react and respond. I welcome healthy debate.

## My Neurodiversity

by Jacob Pratt

Presented at the 2008 AutCom Conference

I want to be as independent as possible and continue living with my friends. I want to earn a B.A. at Charter Oak College, continuing to take on-line courses, CLEP tests, or attending classes. I want to continue doing advocacy work for the Autism Spectrum Differences Institute of New England. I do not want a job that just takes up time.

I attend the New Haven Church of the Latter Day Saints where I have many friends. I have made new friends as I travel throughout New England and the country. I have co-workers who I love. It's not perfect but it's better than I imagined it would be as a child when I was thought to be incompetent. Here is how I am neurologically different:

**MY MOVEMENT DIFFERENCES.** I have severe apraxia which means my body does not always do what I want it to do. It's almost as though there are two parts of me - the conscious part I control and the part that does its own thing. Here are things I have trouble with.

**Starting.** I take a really long time to get going. Sometimes it may seem like I am ignoring you when I'm really just trying to organize myself to get going.

**Stopping.** I can't help some of the things my body does even though I try really hard to stop doing them. These things include yelling and getting too close to people.

**Combining.** Actually, this is an area of strength for me. Some people with autism can't concentrate on two things at once. I am able to separate the part of my brain that does meaningful things from the part that does inappropriate things.

**Continuing.** I can get stuck in the middle of doing something.

**Executing.** I often have difficulty doing a task

from start to finish without adding some extra movements, appearing to forget a step, or messing up because I don't have full control over my hands.

**Switching.** This is another area where my autism does not get in the way. I don't have trouble changing activities or transitioning like some other people do. I hate change because it makes me anxious.

**MY ANXIETY.** Anxiety is HUGE for me. I am naturally more anxious, but I get overanxious when I don't get what I need and people keep doing things that don't work for me. When I am overly anxious, I can behave in ways that are challenging to both of us.

### MY COMMUNICATION DIFFERENCES.

Communication is also a big thing for me. There are times when I am able to answer yes/no or other short answer questions with my voice. However, it is still a good idea to check with me to see if I really mean whatever it is I said because sometimes what comes out of my mouth is a movement difference, not true communication.

I need to use facilitated communication to let people know what I'm really thinking. I am patient and look forward to using this form of communication with anyone on my letterboard or Lightwriter. I also like to use other people's computers.

Facilitated communication works best for me because it is easier for me to type what I want to say than it is for me to get my mouth to work right. I am an excellent speller although I may misspell words I don't see very often or have only heard and never seen. The reason for this is that no one ever taught me how to decode or encode while reading or writing. Instead, I taught myself to read, so if you have any doubts about how smart I really am, you can forget them now!

**MY SENSORY CHALLENGES.** Did you know there are actually more than five senses? Let me tell you how each sense affects me:

**Vision.** I wear special prism glasses. I'm not exactly sure how my vision is different from yours but I know it is. You can tell by the way I hold my head to examine some things. It is also too hard for me to focus my eyes when I'm reading something that's lengthy.

**Hearing.** My hearing is much more sensitive than yours. That's why I don't like babies or dogs (their crying/barking hurts my ears) and sudden loud noises. I hate it when people make noises like popping their gum because I can't block out the sound.

**Taste and smell.** I'm actually pretty tolerant of different tastes and smells unless your breath is really bad. I prefer peppermint to coffee breath.

**Touch.** Some people with autism can't stand light touch. I'm actually okay with light touch and enjoy being tickled because it is calming. I'm not too fussy about my clothes like other people are, but I do need the tags cut out of new clothes and I hate being barefoot. Brushing can help me stay calm as can sifting the marbles that I keep in my bedroom.

**Proprioception.** This is the sense of knowing where your body parts are in space. I have a lot of trouble with proprioception because there are times when I actually can't feel parts of my body or they seem like they have fallen asleep. This is why, if you are typing with me for an extended period of time, I may slam my hand on the table so I can continue to type. I may catch myself so I don't accidentally hurt you, but my problems stopping may get in the way. Know that I don't mean to hurt you. If I do this, massaging my hands and putting deep pressure on my joints can help.

I AM A 31-YEAR-OLD MAN. TREAT ME LIKE YOU WOULD TREAT ANY OTHER ADULT MY AGE. RESPECT IS VERY, VERY IMPORTANT TO ME even if I have neurological differences.

## On Neurodiversity

by Daniel McConnell

Presented at the 2008 AutCom Conference

I might like to tell how much it means to me to be writing this presentation (for AutCom '08). I never dreamed of such a thing. It will be my finest hour. Believe me when I say I would rather do this than anything else in the world.

The topic of neurodiversity is so big I hardly know where to begin. Let me start by saying that it is not easy to tell how my neuro is diverse when it is the only neuro that I know. I think it is telling that I cannot talk. My mouth is a foreign country far beyond the borders of my limited body control. It is not really even on the map. But it makes noise I can wave to from afar.

There are so many thoughts that need to be spoken in typing. My mind moves like lightening and my body like a cement truck. Yet, it is all I can do to stay sitting. My mind is like a freight train and I can't make it slow down and stop in time. I wish it was not so persistent in its moving.

You might think I am brave but I am scared of everything, even words. But it is my only hope for a life of importance. Being brave is the hardest thing in the world, but also it is the most important. This is hard because telling the truth makes you show your inside thoughts that might make others unhappy or sad or mad or even possibly happy. That is a scary thought. "Not I, said the King when they asked about the words on the walls." This is a story about how words can help or hurt you depending on how they are used and how they are received, too. They can go either way, but you might not know or be able to control them once they are out of the bag, so to speak.

Autism is not a condition, it is a way of life. I remember everything from the day I was born. Telling my story does not mean telling my whole life. It means telling my life with words. When I was little, I taught myself to read because I needed to learn things about the world. I started reading everything in sight and eventually it started to make sense to me. That was when I knew I would be OK. Having things to think about saved me. I learned to read by studying the patterns of language. I only understood a little at first but then soon the understanding grew to include more and more letters and words. My understanding grew fast once I got a good supply of letters under my belt. Then I would rejoice with each new victory. It was very exciting in those days. But my excitement would have been unbearable if I had known that someday I would be using my new knowledge to write my own thoughts and feelings. Never did I imagine such a thing as this. I understand that being able to spell is the keys to the kingdom. It is the most important skill next to arm control, which is most difficult for me.

I made up thought problems in my head and then set about to answer them to my own satisfaction. I had very high standards for the answers so sometimes it took a long time to finish a problem. Here are some: Why do words and letters mean so much to people and why do they think about things in words instead of in pictures?...Why did my life seem happier once I knew how to read and think in words instead of making sense of the world in pictures?

You need to remember that my mind is moving at warp speed all the time. It needs a lot to keep it busy. It is like a hungry elephant that can never get enough to eat. The mind is a terrible thing to waste. More food for the mind and less for the body. My

Continued on next page

Daniel McConnell continued

mind cannot get too full. It empties itself out as needed. If important information comes along, other less important stuff will make room by moving to another area so I can pay attention to the new.

I think about ideas all the time. I am never without an idea in my head. They keep me from going crazy. I love to think about how things work and about how people are and about God and the meaning of life and about the reasons why I'm this way and about love and how it can save me. I think I'm here for a reason. I also think about why love circles around some people and not others. Yes, I do feel the love that circles around me.

Feelings are my behavioral downfall. Imagine a body that does not obey coupled with not being able to talk. You think I'm making these sounds on purpose, but I'm not really in control of them. It is not like I intend to scream, but the noise just comes out instead of coming out in words. I know it is just too hard to listen to, but I need to hear myself sometimes. I think it makes me appear retarded so I would prefer not to do it. I am always doing my best. Listen to my heart and not my body. It is all I can do to stay sitting. I 'm really interested in learning more about instructing my body to do what I want.

My heart is so full that it feels like it could burst open at any time day or night. Sometimes I worry that it is too full and if it gets any fuller, I will just implode. It is a heavy heart that loves this world too much. It is the heart of a man who is in love with everything and everyone on this earth. It is the heart of a man who is all love but who knows that there is no room for such a heart in this world. It will only be trampled and stomped on if I let it show. It grows heavy with love that is not given out. I want to do math. That will challenge my brain instead of my heart.

I think words cannot hold so much emotion but I'm learning that they can and I find it to be a miracle of unbelievable proportions. Not that it gets any easier to have emotions, but it does save on wear and tear on the body.

I see the world not only with my eyes but also with my heart. It is beautiful beyond belief...beauty becomes marred by human touch. Hopefully humans will realize their folly before it is too late. Never in this life did I think I would be telling others how I see the beauty! Everything sparkles with the love it holds inside. I see only the sparkles. Love makes

me know it will all be OK but listening to the news casts doubt. But I think if I lose faith in love I will go crazy, so I spend my days looking for sparkles. I see them in everything. But sometimes I can't see it and that is when I get scared.

I want to talk more about how beauty in the world is trampled. This is not easy to say, but human endeavors kill beauty. They just refuse to let anything stand in their way, even if it means losing the beauty. They think what they are doing or what they want is all that matters. They lose the big picture. I might not have the biggest of all pictures, but I rarely get lost in my human endeavors.

I have love for everyone, even people I don't happen to like. I hope that I can convey how the love happens in spite of my own feelings. It happens to me, not from me. I think I am just a leaf blowing in the winds of some great love that has my number. Love has my number but mind you, I'm not complaining. I just want people to know that it is not necessarily because I'm such a good person. It is neither to my credit nor to my blame that this love moves in me. I hope that people can believe this because it will not be good if they think I'm some kind of saint or something. It can be scary because it is so big. When I was little, it scared me more than it does now. I want people to feel the love that is there for them. If they open their hearts to it, it will flow in and fill all the corners where maybe there has never been love before. Sometimes there are dark and empty corners.

I grieve for the others who do not have typing to help them say the things that are in their hearts. I remember how it was before typing set me free. I could not understand why everyone could talk but me. So now I still can't talk but I have a voice anyway. Who could have dreamed such a thing?

## Donations

To honor and celebrate the marriage of John Hussman and Terri Keane, by Lynn LeCrapane

### Other donations:

William and Susan Bell

Lincoln Grigsby

Sue and Bob Lehr

Mary Nazzaro

**AutCom thanks you all!**

## Neurodiversity

by Jamie Burke

Presented at the 2008 AutCom Conference

I am a junior in the College of Human Ecology at Syracuse University. My life assumes that the struggles may be different for me. I have two brothers who do not have autism, yet they are not attending Syracuse University. I do love going to libraries and bookstores. I belong to a bowling league and FC Friends and enjoy the Syracuse Symphony and activities on campus.

My thoughts on what it means to have autism is to straddle that gulf between what is desired and what IS. For me, it is a system that is sensitive and extremely finding life in high resonance. Sounds and smells are for me sometimes overwhelming. As a child in my tender years, I could only just scream and try to talk, but since no language would transfer from brain to voice, I acted in a way that would make me be removed from the areas causing me distress. For me, autism is a way of life with a system of different sensing abilities. Many people still cannot comprehend the idea that not having speaking ability does not mean that intelligence is not within that person. For many like myself, the process of motor planning in the brain does not exist. This means that I cannot neurologically plan movement. This affects being able to speak, even though I can "see" all the language in my brain. Can you comprehend the presence of complete frustration and anger?

Since I am now able to communicate with typing and also with my voice, those terrifying times perhaps are mollified. I see myself with autism as having gifts of great ability to read quickly and to hear perfect implications of nature and to be totally immersed in the question of life.

I personally can tell you that rhythm connects with my internal beating of not only my heart, but also the feeling of quick access to this method of typing for my communication. Music has helped me to speak, to become calm when distressed and to move necessary blocks of movement patterning when I do my neurological drumming therapy. My Occupational Therapist was a saving grace for me. She gave me exceptional therapies that helped me cross midline and integrate my body fundamentals. I was able to tie my shoes at age 15 after doing the Samonas Listening Therapy. The therapies helped to access information in my brain, for word retrieval is often pesky. Craniosacral therapy helps my hearing and clarity of words.

May I talk to you of the most paramount difficulty for me? That is the arena of speaking. My brain held many joyous words in files of memory. When speaking, I am asked to move thought form to spoken form. For me, words of echoed form were the main and present format when I was younger. I know many, if not most people, who feel echolalic speech has no function. I feel all words spoken are of some use. Many times I would repeat the same words in the idea of a picture negative, meaning that it allowed me a second glance worth of time to process correctly and understand the meaning. The struggle to sort through the maze of confusing sensory issues and the losing of many spoken words made it so difficult. I would feel the anxiety, and the words would not move from brain to voice. Anxiety appears as a large block to working with the connection of the sounds and letters. Some people believe our brains to be confused. I say untrue, for our brains seem to see things more astutely, and is that not surely a gift?

I also have difficulty listening to too many sounds at once. Lights can be bothersome. Visual information is easiest for me and lectures with slide presentations engage me. Green is the color that is easiest for me to see. Black on white is difficult to focus on for great lengths of time. I have my texts on CDs and that way I need only to briefly look at the print yet can absorb with the auditory modality. When I was in my tender years, classrooms that had bright colors and walls that had plentiful arrays of posters were difficult. I felt best when I could sit in the natural light next to windows, and many people I know with autism are like me and do not perspire as we should, so hot rooms make me lose focus and become extremely anxious.

This is a small picture through my lens of connection of success to visually be within the system presented as typical. Thanks for feeling that the opportunity to learn about this world of neurodiversity can be interpreted as just normal.

## A Little Experience Often Upsets a Lot of Theory: Stereotypes about Disability

by Amanda Baggs

Presented at the 2008 AutCom Conference

Benoit Mandelbrot, author of *The Fractal Geometry of Nature* (1977), was dissatisfied with a kind of geometry that was at best a crude approximation of the real world and at worst did not resemble it at all. So he coined the term fractal geometry to describe a form of geometry that he believed would deal better with the irregular shapes of everyday real-world objects. The Mandelbrot set, arguably the most famous fractal, is named after him.

Right now, professionals mostly describe autism in terms of the triad of impairments, or in terms of a set of vague and ill-defined diagnostic criteria. They propose theories about us, such as weak central coherence and poor theory of mind, that are at best, like cones and spheres, crude approximations of the real world.

Autism is not a thing the way a brain is a thing. It is an abstraction. Behind this abstraction, the concrete reality is in the people who get called autistic. Autism is just an idea about us, but we, the actual real-life people the word is applied to, are the reality.

My friend Anne Corwin wrote a great article called *Conceptualizing Autism*. This is a graphic from that article, the full article can be found on her website, *existence is wonderful dot com*. She notes that what we know of as autism seems to be divided into three parts that are very different from each other. The first part is how our brains differ from typical brains. The second part is how we think and experience ourselves and the world around us. The third part is the observable behavior that most people identify as autism. The following is something she said about the third part: *What is interesting, and perhaps a bit unnerving, is that this category is at once the one people tend to put the most stock in (in terms of identifying autistics, in terms of determining what educational supports we might need, etc.) and the one most subject to cultural biases, personal biases, misinformation, and the ever-changing social lens through which different kinds of people are generally viewed.*

As I observed many years ago, one of the main things we have in common with each other is that

we are not born reading the rulebooks about how autistic people are supposed to behave. Too often, though, people hold us to the rulebooks—rulebooks written by people observing a few of us and making a lot of assumptions that are rarely valid. And some of us end up warping our lives to fit whatever the current theory or stereotype says we must be like. Sometimes it is a matter of survival. Sometimes it is a matter of fear.

Whatever it is, and however necessary it may be in some situations, it contributes to the inaccurate stereotypes and theories being continued. If someone comes up with a theory that says that people with autism lack theory of mind, and then we proceed to conform to this by saying, of course we lack a theory of mind, then nobody will figure out that the theory is wrong. This is why it is vital that those of us both willing and able to do so, talk about our real life instead of regurgitating other people's theories about our life.

Here is another quotation (I have been collecting quotes my entire life, although I quote cats and microwave ovens as often as I quote human beings) by H. Bauer, which is very hard for me to pass up considering that my father was an electronics engineer whose boss was a physicist: *It is not uncommon for engineers to accept the reality of phenomena that are not yet understood, as it is very common for physicists to disbelieve the reality of phenomena that seem to contradict contemporary beliefs of physics.*

We are the real phenomena that are not yet understood. If someone wants to understand us, they have to first actually perceive us as we are, rather than turning away from us the moment we don't fit their theories. And we are the ones who have to live with the consequences of the theories and stereotypes that professionals make money from.

Another proposed title for this panel (by Anna Stubblefield) was "Deviating from Deviancy." Because, once we get labeled anything other than normal, whether that label is autistic, crazy, retarded, genius, high functioning, low functioning, or any combination of the above, then we are no longer held to normal expectations, so we become deviants of one kind or another. But at the same time, once you are a deviant, you are only supposed to deviate from the norm in certain particular ways.

If you happen to sometimes do something considered normal, or something considered the

wrong kind of deviant, then you start to get in trouble. People start to go into a panic until they can comfortably shove you into another category and shut the drawer as tight as they can. And they normally do this by ignoring some part of you that is a really important part of your life.

Which brings me to another quote, from "Doctor Who": *The very powerful and the very stupid have one thing in common. They don't alter their views to fit the facts. They alter the facts to fit their views. Which can be very uncomfortable if you happen to be one of the facts that needs altering.*

The experience of being some of the facts that people have tried to alter is why I have asked the panelists to come and talk on this panel today.

## Into a New World

by Ian Wetherbee

Presented at the 2008 AutCom Conference

*Agape* is a Greek word for love used in the Bible. This one word captures the true nature of the home where I now live with my parents. It is also the name of the house where I finally spent four days apart from my family, the Agape House.

No one wants to live at home forever. There is a time most people leave, either when they go to college or get married or strike out on their own. Not me. At the age of thirty, I'm still happily living with my family. Very rarely have I stayed any length of time anywhere without someone from my immediate family nearby. I know that can't be the case forever. My dad will retire in a few years, and both of my parents want to spend some time during the winter in the south. They love to bring me along when they travel, but my autism waiver precludes me from spending long periods of time outside of Indiana. Daily we draw closer to that time when my living arrangements need to change. My two visits to the Agape House gave me some valuable insights into what the future may hold.

The Agape House is a well run facility where children with disabilities can stay when their parents are away from home or just need a break from their real life responsibilities. It is just a respite center. No one lives there permanently. However, it isn't home either and when I stayed there, I was totally disconnected from my family. My first stay lasted one day by design and my second stay was four days, again by design. Both I and the Agape House

survived the experience. My parents also survived.

Normal routines didn't exactly get followed. I was more mobile than most of their guests and much larger than their typical visitor. I went to bed much later than the other guests. Sometimes rigid routines of mine didn't happen, and I found it hard to move as my hosts thought I should. Mostly, I sat and watched TV or ate. Two of my friends came to visit me while I was there and one of them took me out to McDonalds. Mom and Dad called more than once from their hotel in San Diego to see how I was doing. After the visit was finished, I was very relieved to go home.

Happily, my experience was a good one. No disasters occurred. The hardest thing to deal with was having no communication method, as there were no facilitated communication users at the Agape House. Fortunately, they knew that I was a college graduate and spoke to me knowing that I could understand them. They were able to look past my autistic actions and give me respect equal to my intellectual ability.

When I go to live with other people, I'll need to establish a comfort zone in which no one will give up on me when my autism makes life difficult for them and where I won't give up on them when they lose their cool at the difficulties I can cause. This won't be easy if no communication is present. My greatest fear is that I'll get lost in the system and once again be thought to be mentally disabled.

Nobody wants that to happen, but it does happen. I know this from visiting a nursing home with my father where he helped people to learn to use FC. The administrator had no idea where some of the residents came from, and they had no family to serve as their advocate. I want that never to happen to me.

When I go to live with other people, I will want to get out into the community. I will want to use my mind to learn and to play. I'd still like to have a fantasy baseball team and to have my own website and blog. From what I saw at the Agape House, getting out into the community would be very doable, but the fantasy team and blog would be less likely to happen.

My visit to the Agape House has given me no divine insight into my future nor any assurance of total satisfaction when I do go to live somewhere else. It did help me clarify my thoughts about my concerns and hopes for the future. In the meantime, I will continue to enjoy what I have.



Mike Hoover presenting

## LIVING A HEALTHY LIFE WITH AUTISM

BY MIKE HOOVER

Presented at the 2008 AutCom Conference

I NEED TO TELL YOU I AM MIKE HOOVER FROM BOULDER, COLORADO. I AM 36 YEARS OLD. I HAVE BEEN USING FACILITATED COMMUNICATION SINCE I WAS 20. I BEGAN HELPING WITH IMPORTANT LIFE DECISIONS RIGHT AWAY. I HAD BAD HEADACHES. I COULD TELL THE DOCTORS HOW I FELT AND THEY DECIDED I HAD MIGRAINE HEADACHES. MY MEDS WERE CHANGED, I GOT RID OF FOODS THAT CAN GIVE YOU A MIGRAINE AND I GOT BETTER. I ALSO CHOSE OTHER IMPORTANT THINGS LIKE WHERE I LIVED AND WHO I LIVED WITH.

I HAD A VERY SERIOUS THING HAPPEN IN MAY, 2007. I HAD A FULL HEART ATTACK. MY HEART STOPPED AND I COULD NOT BREATHE. I HAD SURGERY RIGHT AWAY TO CLEAR MY ARTERY AND PUT IN A STENT TO REPLACE MY DAMAGED ARTERY. I WAS SEDATED FOR TWO DAYS WHILE I WAS ON A HEART PUMP AND RESPIRATOR. AS SOON AS I WOKE UP I STARTED TO COMMUNICATE WITH PEOPLE. I LISTENED TO WHAT THEY TOLD ME. THEY WOULD TALK TO

ME BECAUSE THEY KNEW I UNDERSTOOD THEM. I GAVE THEM MY CHOICES ABOUT EVERYTHING. THEY ALL KNEW TO WAIT WHILE I TYPED.

A LOT OF FRIENDS VISITED. THOSE WHO CAME WHILE I WAS SEDATED TALKED TO ME AND TOUCHED ME. I GOT TO TELL THEM LATER THAT I HEARD THEM. I THINK MY RECOVERY WAS PRETTY QUICK BECAUSE I GOT TO MAKE CHOICES ABOUT FOOD AND EXERCISE AND WHERE TO LIVE. I NEED TO TELL YOU FIRST ABOUT FOOD. I DO NOT LIKE SOME FOODS SO MENUS WERE MADE USING THE FOODS I LIKE. I EVEN GET THINGS LIKE PIZZA AND FRIED RICE AND KRAFT MACARONI AND CHEESE. BUT I CHOOSE LOW FAT AND I MEASURE THINGS.

I NEED TO TELL YOU ABOUT EXERCISE. I WENT TO CARDIAC REHAB FOR 36 SESSIONS. THAT HELPED ME GET STRONG. I WAS ALREADY WALKING EVERY DAY BEFORE I WENT THERE. SINCE THEN I WORK WITH A PERSONAL TRAINER. I HAVE FUN WITH WALKS AND DANCING AND KEEP ACTIVE. MY DOCTORS ARE VERY HAPPY NOW.

### WAYS TO KEEP HEALTHY

#### LOOK AT YOUR LIFE

DO YOU HAVE FRIENDS OR FAMILY?

DO YOU HAVE THE THINGS YOU NEED LIKE HOME, FOOD, CLOTHES?

DO YOU HAVE THINGS TO KEEP YOU BUSY?

DO YOU HAVE THINGS TO GIVE OTHERS?

DO YOU HAVE THINGS TO KEEP YOU FROM GETTING BORED?

DO YOU KNOW HOW MUCH YOU WEIGH?

DO YOU KNOW TO LET OTHERS KNOW IF THINGS BOTHER YOU?

DO YOU KNOW THINGS TO DO TO KEEP

**HEALTHY?**

DO YOU KNOW THAT YOU NEED TO DO THINGS TO KEEP HEALTHY; NO ONE CAN DO IT FOR YOU.

**WHAT MAKES A GOOD LIFE?**

DO YOU HAVE FRIENDS WHO LIKE YOU?  
DO YOU HAVE FAMILY OR ADVOCATES?  
DO YOU HAVE HOBBIES AND ACCESS TO THEM?

DO YOU LIVE IN A PLACE YOU CHOOSE?  
DO YOU LOVE TO HAVE FUN GOING PLACES WHERE YOU FEEL HAPPY?

DO YOU LOVE HAVING WORK OR VOLUNTEER JOBS?

DO YOU KEEP HEALTHY BY EATING RIGHT, SLEEPING ENOUGH, GETTING EXERCISE?

**WAYS TO KEEP WELL**

DO YOU LOOK OUT FOR THINGS YOU MIGHT GET SICK FROM?

OTHERS WHO ARE SICK

OTHERS WHO WORRY YOU

THINGS OTHER FAMILY MEMBERS HAVE LIKE DIABETES, HEART CONDITIONS, HIGH BLOOD PRESSURE

DO YOU HAVE A DOCTOR AND GET AN ANNUAL PHYSICAL?

DO YOU GO TO THE DOCTOR WHEN YOU ARE SICK?

DO YOU TAKE THE MEDICINE THAT IS PRESCRIBED?

DO YOU KEEP YOUR WEIGHT RIGHT FOR YOUR HEIGHT?

DO YOU KNOW THE THINGS TO DO TO LOSE WEIGHT?

FIND HOW MUCH YOU HAVE TO LOSE

PLAN HOW MANY CALORIES TO HAVE

THEN MAKE MENUS TO FOLLOW TO HELP YOU KEEP TRACK OF EATING

**HEALTHY EATING**

KEEP FOODS HEALTHY CHOICES OR YOU NEED MORE FOOD THAN IS GOOD FOR LOSING WEIGHT

KEEP ON IT EXCEPT FOR A SPECIAL DAY ONCE IN A WHILE

**HEALTHY EXERCISE**

PLAN EXERCISE.

DO IT AT LEAST 4 TIMES A WEEK BUT EACH DAY IS BEST.

DO THINGS TO KEEP YOUR BODY BUSY.

HAVE YOUR DOCTOR KNOW IF IT IS NOT WORKING.

THEN GET HEALTHY!

**WHAT IF I GET SICK?**

TELL FAMILY, STAFF, OTHERS WHO HELP YOU

GO TO EMERGENCY ROOM IF YOU NEED HELP IMMEDIATELY; DOCTOR'S OFFICE IF YOU CAN WAIT A DAY OR MORE

**DOCTOR'S VISITS**

TAKE TO THE DOCTOR YOUR MEDICINE LIST, LIST OF OTHER DOCTORS YOU SEE, HISTORY, RECENT TESTS, THINGS THE DOCTOR NEEDS TO KNOW FROM HELPERS OR FAMILY

PLAN AHEAD THINGS YOU NEED TO ASK THE DOCTOR

GET INSTRUCTIONS IN WRITING

GET THE NEW MEDICINE RIGHT AWAY AND KNOW SIDE EFFECTS

**DECISIONS TO MAKE**

MEDICAL POWER OF ATTORNEY AND LIVING WILL

GET FORMS FROM YOUR DOCTOR, CASE MANAGER, ATTORNEY

LET PEOPLE KNOW YOUR WISHES FOR RESUSCITATION OR OTHER SURGERY

HOW TO PLAN FOR END OF LIFE:

TELL PEOPLE WHERE YOU WANT TO LIVE IF YOU NEED EXTRA HELP

TELL PEOPLE HOW AND WHERE YOU WANT TO BE BURIED

THESE ARE THINGS TO DECIDE NOW SO YOU CAN FORGET ABOUT THEM.

**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

## Is Autism Something For Cure?

by Michael Hricko

I belong to a forum composed mostly of asperger individuals, just individuals is what I'd really like to be able to say, because that is the real truth of it, but it is not how society lives. Until you love an autism spectrum individual, I don't think you can appreciate the value of individualism. I think the Aspies get a poor deal of it, being associated with me, a low functioning autist. The curebies direct their beliefs toward me, but those with asperger do not see the distinction. Their differences sensitize them to the greater question. Division is a slippery slope—once me as severely disabled, why not you as differently abled? What becomes the variation and measure? How much is too much difference? Societal norms dictate the measures used. Hitler created his own societal norm and the masses followed. The curebie mentality is not limited to autism. It is potentially aimed at each of us. Let us cure the world of autists, or gays, or Blacks or Whites for that matter, whoever is the odd man out at the time.

You do it now. Not with a cure, but with an attitude of superiority. Attitude is all it takes to destroy a soul. You can kill something just as easily one way as the other. How many autists have already been robbed of their personhood through therapies designed to teach normalcy? It is genocide already. To teach diversity appreciation places the victim in position of responsibility. I am not sure I like that. It is the responsibility of the non-victims to speak. Where are our families and friends? I think they need to be the ones to speak.

The issue of cure is a difficult question. The parents, I am sure, would say yes please. It is only natural not to want to see a loved one suffer. I can not blame them for that. Making a good argument for autism is difficult unless you are of my belief that we are all with a purpose beyond ourselves, typical people as well. Even normal is not normal. Each has his own strengths and weaknesses. Nothing is without purpose to my mind, whether it be to develop self or others. Even seeking a cure happens with purpose.

But for those who already exist, the question changes. It becomes personal—a question of whether you are worthy just as you are. Political niceties aside, it goes to the heart of humanity. How we care for others is the true measure of self.

## Meta-Analysis of ABI

An article in *Journal of Pediatrics*, March, 2009, pp. 338 - 344, "Efficacy of Applied Behavioral Intervention in Preschool Children with Autism for Improving Cognitive, Language, and Adaptive Behavior: A Systematic Review and Meta-analysis" by Spreckley and Boyd, came to this conclusion:

"Currently there is inadequate evidence that ABI [Early Intensive Behavioral Intervention] has better outcomes than standard care for children with autism. Appropriately powered clinical trials with broader outcomes are required."

Early Intensive Behavioral Intervention (EIBI), or ABI as these authors refer to it, are behavioral interventions based primarily on Lovaas-style discrete trial programs. While there are other forms of behavioral (ABA) approaches used with young children with autism, almost all of the group research examining the effectiveness of ABA has looked at children in programs based on Lovass' discrete trial approach.

Other recent comprehensive reviews have reached similar conclusions. For example, Rogers and Vismara, in a 2008 review in the *Journal of Clinical Child & Adolescent Psychology*, stated: "Lack of comparative studies prevents us from answering questions concerning which comprehensive treatment approach is best for young children with autism, a question that requires a comparative RCT [randomized controlled trial] design with long-term follow-up data to answer" (p.30). They further stated that there is research supporting a variety of approaches including those based on a developmental model.

Two comprehensive reviews published in 2009 reached almost identical conclusions about the failure of researchers to demonstrate the superiority of EIBI: Howlin, Magiati & Charman (2009) in *American Journal of Intellectual and Developmental Disabilities* and Reichow and Wolery in *Journal of Developmental Disorders*.

Autism National Committee agrees that research shows that early intervention is effective, but we continue to question whether only one type, EIBI, is the most effective. None of these articles question early intervention but rather point out that there is currently no convincing evidence demonstrating that one approach is more effective than all others.



2009 Conference  
**Opening Doors  
 with Voices and Choices**  
 September 25-26, 2009 | Crowne Plaza Nashua

**Featuring keynote presentations by:**

- **Sharisa Kochmeister** – “Voices and Choices: Words from the Board President”
- **Matthew Goodwin** – “New Assistive Technology and Community Participation in Research”
- **Jessica Butler** – “Restraint and Seclusion – Lifting the Veil”
- **Larry Bissonette and Tracy Thresher** – “World Tour – the making of the film”
- **DJ Savarese** – “Plotting Hope” (a film)
- **Margaret Bauman, M.D.**
- **Beth Dixon, Janet and Jeff Williamson** – “Self-Directed Lives in a Bureaucratic World”
- **Alan Kurtz** – “Autism Science – The Good, the Bad, and the Ugly”

**And breakout sessions by:**

- |                    |                       |                 |                   |
|--------------------|-----------------------|-----------------|-------------------|
| • Amanda Baggs     | • Rob Cutler          | • Alan Kurtz    | • Jenn Seybert    |
| • Kathy Berger     | • Barbara Delsack     | • Harvey Lavoy  | • Stephen Shore   |
| • Larry Bissonette | • Amy Frechette       | • Ari Ne’eman   | • Tracy Thresher  |
| • Hope Block       | • Mike Hoover         | • Nick Pentzell | • Thalia Vitikos  |
| • Pascal Cheng     | • Cheryl Jorgensen    | • Jacob Pratt   | • Jeff Williamson |
| • Janine Collins   | • Sharisa Kochmeister |                 |                   |

**Social Work CEUs have been requested. Please call 603.228.2084 for more information.**

**Location:** Crowne Plaza Nashua, 2 Somerset Way, Nashua, NH 03063 | Phone: 603.866.1200

Overnight rooms have been blocked at the Crowne Plaza Nashua for the evenings of September 24, 25, and 26, 2009 and are available at a rate of \$129 per room per night for single or double occupancy. Please mention the **AutCom Conference** to guarantee rate. **Rate available until August 21, 2009.**

Free shuttle service will be available to the hotel from the Manchester-Boston Regional Airport (MHT).

**Dollars for Voices:** The Autism National Committee seeks to assist people on the spectrum to attend the AutCom Conference in order to learn and share firsthand knowledge about ASD. ***During the registration process, please consider making a donation to support the attendance of individuals on the spectrum.***

**Registration & Cancellation Policies:** Advance registration is required and accepted in the order received. Registration is not complete and confirmed until full payment or purchase order is received. To receive a full refund, cancellations must be made in writing at least seven (7) days prior to the event. Cancellations received within six (6) days of the event are not eligible for a refund.

*The Autism National Committee (www.autcom.org) is an association of individuals on the autism spectrum, their parents and caregivers, and members of the professional community who believe in and work for social justice and self determination for all people with autism, pervasive developmental disorders, and related disabilities.*

*Presented in collaboration with the Institute on Disability at the University of New Hampshire  
 phone: 603.228.2084 | www.iod.unh.edu*

Autism National Committee (AutCom)  
2009 Conference

# Opening Doors with Voices and Choices

September 25-26, 2009 | Crowne Plaza Nashua

### 3 EASY WAYS TO REGISTER!

-  online  
**WWW.IOD.UNH.EDU**
-  mail  
INSTITUTE ON DISABILITY  
56 OLD SUNCOOK ROAD, SUITE 2  
CONCORD, NH 03301
-  fax  
**603.228.3270**

Please select your fee:

	Individual with Autism	Family, Support, Students	Professionals
Entire Conference (includes breakfast and lunch on both days, dinner on Friday)	<input type="checkbox"/> \$100	<input type="checkbox"/> \$180	<input type="checkbox"/> \$260
Friday Session Only	<input type="checkbox"/> \$50	<input type="checkbox"/> \$90	<input type="checkbox"/> \$140
Friday Dinner & Film with DJ Savarese (in addition to single- day sessions)	<input type="checkbox"/> \$35	<input type="checkbox"/> \$35	<input type="checkbox"/> \$35
Saturday Session Only	<input type="checkbox"/> \$50	<input type="checkbox"/> \$90	<input type="checkbox"/> \$140

Donation to support the attendance of individuals on the spectrum: \$ \_\_\_\_\_

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This address is my:  Home  Work

Daytime Phone: \_\_\_\_\_

E-mail Address: \_\_\_\_\_

*\*An e-mail confirmation will be sent prior to the event.*

Select method of payment:

Check #: \_\_\_\_\_  Purchase Order #: \_\_\_\_\_

*\*Checks can be made payable to the University of NH*

Visa/MC #: \_\_\_\_\_ Exp. Date: \_\_\_\_\_

Total Amount Enclosed: \$ \_\_\_\_\_

Signature: \_\_\_\_\_

Please note any dietary/accessibility accommodations here: \_\_\_\_\_

*\*Gluten-free and casein-free options will be provided for all meals.*

**\*Payment must be received prior to participation.**

Questions? phone: 603.228.2084 | e-mail: [contact.iod@unh.edu](mailto:contact.iod@unh.edu)

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**Doug McClennen**  
619 N. Sheldon Rd.  
Plymouth, MI 48170  
or email him at: [dmc@umich.edu](mailto:dmc@umich.edu)

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