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THE COMMUNICATOR

A Publication of the Autism National Committee


Dr. Margaret Bauman

Impressions

AutCom Conference 2009

by Char Brandl

I just returned from the Annual Conference of the Autism National Committee (AutCom) and am filled with awe and inspiration. What sets this particular group apart from the rest is that it is run by and for people with autism, with a strong focus on all that is good and positive about being somewhere on the autism spectrum. I have been attending their conferences for several years and have never been disappointed.

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President's Letter

by Sandra McClennen

The success of the fall conference is a tribute to the hard work and creativity of the members of AutCom's Conference Committee and to Mary Schuh and her team at IOD. We thank you all!

Improving the life experiences of people on the autism spectrum was addressed in many ways. New research, such as that being done by Dr. Matthew Goodwin and his students at M.I.T. and by Dr. Margaret Bauman (Integrative Healthcare for Individuals with ASD), are giving us all new insights into the dynamics of autism. See related articles in this newsletter.

Important warnings were given by Jessica Butler, who urged support for legislation protecting children from abusive interventions, and by Alan Kurtz, who warned about practitioners who use scientific terms to promote their own self interest. Both of these warnings take on additional significance in light of a recent article in the L.A. Times (12-7-09), "Autism: Kids Put at Risk" by T. Tsouderos and P. Callahan. This article focuses on desperate parents who try unproven and often abusive "alternative" therapies that aren't based on sound science and may actually hurt their children.

An interesting issue for us to attend to is the revision of The Diagnostic and Statistical Manual of Mental Disorders (DSM), published by the American

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(President's Letter continued)

Psychiatric Association (DSM-IV being revised to become DSM-V). It is the diagnostic standard in psychiatry and is also used by health insurers. The committee responsible for the revision has proposed that Asperger Syndrome and a mild form of autism, Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) be folded into a single broad diagnosis, Autism Spectrum Disorder — a category that would encompass autism's entire range, or spectrum. Is this a good idea or not in the best interests of people on the spectrum? AutCom needs to enter this debate!

One proposed change that AutCom does support in the DSM revision is including the array of other health problems that commonly accompany a specific disorder. For autism, this would most likely include anxiety, attention disorder, gastrointestinal problems, seizures, and sensory differences such as extreme sensitivity to noise. I wonder whether we can influence them to include movement differences also.

Becoming Part of the Community

by Jenn Sybert

I am currently a graduate student, seeking an MA in Disability Studies at Syracuse University. This along with my BA in Psychology has provided me with a solid basis on which I stand as an advocate for myself and others who have disabilities.

In my course work I have discovered that having a disability in any form is hardly a death sentence but a platform on which an individual has an opportunity to seek a place for her/himself in our society and graciously take her/his place alongside cultural peers.

I have personally sat in a workshop setting and a day habilitation center. I watched folks who had potential to develop and get out of the security of those places and become a thriving member of a community but who, because of many reasons unknown to me, stayed in a basement program with no windows, only artificial lighting, and I watched them rot...my perspective.

I watched and was part of using time coloring pictures, identifying coins, sequencing, and matching colors, and the life skills were even less impressive.

I knew I could communicate and I knew I was not retarded but up until that point in time, my life dictated this. It was a life of frustration and rage. Then, on July 18, 1995, I was evaluated for facilitated communication, and that day my label of being retarded was removed and having intelligence was instituted upon my words as I typed for the first time and was now set free.

I decided that from experiencing sitting in silence for twenty four years, I was committed to become a voice of listening, guiding and deciphering information to access help for these individuals and their supports.

Jenn Sybert

My family rallied around me because they believe in their children, and they work together by reaching out in support for my sister and me to reach our fullest potential in this life.

Sitting in a sheltered workshop were individuals who have motor skills and decisive traits for promise in their community, stacking cups, putting wires in bags, paint-sets together, and other jobs that were a good use if they were not in a sheltered workshop being paid a nominal wage. Why can't this be transferred into a community setting where they could earn minimum wage? The staff was very good and kind to us, but my point is why do workshops segregate these folks when they are capable of being part of their community? They are hidden and tucked away where the normal everyday Joe does not know they exist and therefore never gets the opportunity to interact with them on a personal, day to day basis.

This is one of the major reasons why disabled individuals are ignored and not included in today's society. We are considered outliers and to be flashed a brief, courteous smile as normal folks pass by us.

As for those in day habilitation centers, there is also potential lying within these folks waiting to be taught and coaxed out as members of their community. I met a young man who lived across the street from a fire house and loved to visit. Having heard this, I asked the aide why is it necessary that he spend every day in the day habilitation program? Why can't arrangements be requested of the fire company allowing him to volunteer and let him wash the fire truck, help fold the hoses, clean and sweep the fire house?

Some of my other thoughts about how individuals can feel a sense of belonging to their community:

- Why not have a newspaper drive where everyone can participate in shredding papers for farmers for their livestock, for cages in the humane society kennels. It would be great to be a volunteer to help clean the cages of these animals, feed them or just love them until they are adopted.
- How about volunteering at your local "Y" to fold towels and in exchange maybe work out a deal where you can swim or use the workout machines with a trainer during her/his downtime.
- In the fall, walk around the neighborhood and seek out the elderly. Volunteer to rake leaves and in winter, shovel their walks. Visit those in nursing homes who do not have friends or family.
- Participate in the local community garden club. See if the day program can establish their own flower garden and take care of it.
- Make cookies and simple crafts during the various holidays and visit the neighborhood Head Start to connect with the children.
- Find out where the local food banks are located and have a canned food drive to replenish the shelves. Here is another area where no matter how compromising the disability, everyone can participate.
- The same goes for collecting old eye glasses for the Lion's Club. This draws awareness, and they see the goodness that comes from being thoughtful.
- Collect cell phones for the military.
- These are a few ideas of how individuals can feel a sense of belonging to their community and at the same time educating them as to their existence outside of their weekly jaunt through Wal-Mart!

From my experience and my education thus far, I'm seeing for myself how those who sit with disabilities are stigmatized and thought to be have severe limitations. Sadly this is not explored. These programs should turn their focus on potential, encouraging the community to see that through training and support staff on a one to one basis, these people have faces, names, personalities, sense of humor and feelings.

My dream is to have an all–inclusive culture where the individuals who have disabilities are not simply dismissed by a quick smile in passing, but have a conversation during a meal with friends and co-workers. Disabled folks are a forever entity in society, whether their disability is hidden or evident.

Inclusion is the next important requirement to be instituted and adapted to.

Best Wishes to all of our wonderful members and followers. May the New Year bring everyone success in making the world we live in a better and safer place!

Support Legislation to Protect Children from Abusive Interventions

by Jessica Butler

Across America, schoolchildren are placed in restraints and confined in seclusion rooms that are locked or from which they cannot exit. Children are injured, traumatized, and have died. This year, Congress is likely to take up legislation to strictly limit their use. Legislation will likely be introduced late this fall in the House Education and Labor Committee, chaired by Congressman George Miller.

I spoke about this issue at the recent Autism National Committee conference because protecting people with disabilities from restraint and seclusion is a principal goal of AutCom. The recent report by the Council of Parent Attorneys and Advocates (COPAA), "Unsafe in the Schoolhouse" found that many restraint/seclusion cases involved children with autism and that restraint/seclusion were often used without parental consent and in place of positive behavioral intervention plans. According to a Government Accountability Office (GAO) study, restraints and seclusion have been abused in hundreds of reported cases. Examples include a 7 year old purportedly dying after being held face down for hours by school staff, 5 year olds allegedly being tied to chairs with bungee cords and duct tape by their teacher and suffering broken arms and bloody noses, and a 13 year old reportedly hanging himself in a seclusion room after prolonged confinement.

As the autism community considers these issues, a few key themes emerge.


Jessica Butler

(1) Congress should prohibit the use of restraint and seclusion except in true emergencies, meaning that the child or others are in imminent danger of serious bodily injury. Abusive interventions are never appropriate for less serious risks, to control behavior, as punishment, or for destruction of property.

(2) Because of the very serious dangers they pose, the following techniques should be prohibited: restraints that interfere with breathing, mechanical and chemical restraints, and locked seclusion rooms.

(3) Schools must provide students with effective positive behavior supports developed as part of a comprehensive, professionally-developed program of accommodations, supports, and interventions. The use of restraint and seclusion places children at grave risk of physical and psychological harm and violates their dignity and basic human rights to be free from abusive treatment.

(4) School districts should not be allowed to circumvent restrictions on restraint and seclusion through the IEP; the same law must apply to all children. The GAO reported that most cases of restraint and seclusion involve children with disabilities, so allowing school districts to use IEPs to continue their use is untenable.

(5) Roughly half of the states do not limit restraint/seclusion, meaning that a distance of 30 miles may determine whether a child is safe. It is important to protect laws in states that are stronger than what the federal law will be. Rather than argue that national legislation is needed because there is a "patchwork" of different state laws, it

is important to argue that federal legislation is needed because restraint/seclusion is a serious national issue that exposes children to trauma, injury, and death. No child is hurt because a state has a stronger law; the problem is with those states that have weak or no laws.

(6) Parents must receive written reports within 24 hours if the techniques were used so they may watch children for injury and psychological trauma and work with schools to create better a environment for their child. Data must also be reported to the State and federal Departments of Education and be made available to the public. Sunshine is vital.

Jessica Butler is the author of *Unsafe in the Schoolhouse: Abuse of Children with Disabilities* (COPAA 2008). She previously was Chair of the Board of Directors of the Council of Parent Attorneys and Advocates, and served as Congressional Affairs Co-Chair from 2006 to 2009. She is an attorney and the parent of a child with autism and epilepsy who loves Sesame Street with all his heart. She actively works with Congress and her state legislature to protect the rights of children with disabilities

Additional Resources:

- House Education and Labor Committee website, http://edlabor.house.gov/
- GAO, Seclusions and Restraints: Selected Cases of Death and Abuse at Public and Private Schools and Treatment Centers, GAO-09-719T (May 19, 2009) http://www.gao.gov/products/GAO-09-719T
- Jessica Butler, *Unsafe in the Schoolhouse*, Council of Parent Attorneys & Advocates, Inc. http://www.copaa.org/pdf/UnsafeCOPAAMay_27_2009.pdf
- The Alliance to Prevent Restraint, Aversive Interventions and Seclusion (APRAIS) website, which includes substantive research and also advice for parents/advocates http://aprais.tash.org/
- You can call Members of Congress, 202-224-3121, or use their email sites: House of Representatives, http://writerep.house.gov, and Senate, http://www.senate.gov/ and click on Senators. Email is preferred to postal mail due to 10-14 day delays for anthrax screening.

Read late breaking news below!

News Note: December 9, 2009 12:15 PM

WASHINGTON, D.C. – **U.S. Reps. George Miller** (D-CA) and **Cathy McMorris Rodgers** (R-WA) today introduced legislation that would, for the first time, **protect all children in schools from harmful uses of restraint and seclusion**. The legislation embodies principles outlined in a letter U.S. Education Secretary Arne Duncan sent to Miller today. **U.S. Sen. Chris Dodd** (D-CT) is expected to introduce companion legislation today in the Senate.

A U.S. Government Accountability Office report released last spring exposed hundreds of cases of schoolchildren being abused as a result of inappropriate uses of restraint and seclusion, often involving untrained staff. In some cases, children died. A disproportionate number of these victims were students with disabilities.

"Something is very wrong when our children are at risk in their own classrooms," said Miller, the chairman of the House Education and Labor Committee who requested the GAO's investigation. "In some cases, the abuses these kids are suffering are nothing short of torture inflicted at the hands of the very staff we entrust with their safety. Today is a critical first step toward finally ending this nightmare of abuse and ensuring that all classrooms are safe for students, their teachers, and the entire school communities."

Call to Action

Our website, www.autcom.org, now features a Call to Action, to acquaint readers with a current issue on which they can influence the debate. Our current Call is to ask Congress to protect children from abusive interventions. This was the primary reason for the formation of AutCom and continues to be an issue today. Let's finish this job once and for all! In this issue, Jessica Butler has an article telling how.

Integrative Healthcare for Individuals with ASD

by Linda H. Rammler, M.Ed., Ph.D.

"ASD children, adolescents and adults can and often do have medical issues that have largely gone unrecognized and unaddressed" was the central issue addressed in a plenary session by Dr. Margaret L. Bauman, long-time friend of AutCom who has done amazing work in helping parents, professionals, and people with autism diagnoses themselves to understand the neurological underpinnings of ASDs (autism spectrum differences). Dr. Bauman is a pediatric neurologist affiliated with Massachusetts General Hospital and other places who founded the LADDERS program now housed in Lexington, Massachusetts.

In her presentation, Dr. Bauman pointed out several truths.

- When neurotypical children are "coming down with something" or already physically ill, rates of their problem behaviors become elevated.
- Problem behaviors overall have been linked to such conditions "as constipation, allergies, premenstrual syndrome, ear infections and urinary tract infections."
- Problem behaviors in any patient seem less related to the physical illness per se than to the "degree of pain or discomfort experienced by the individual."
- There are data suggesting that people with the "fewest communication skills are likely to experience the most pain over time." (Dr. Bauman specifically referred to "cognitive impairment" but, since so many people thought to have an intellectual disability + behavior = autism have been shown to be intellectually competent once given a functional way to communicate, this author is purposefully avoiding this term. In other words, if you can't tell us what you're feeling, we don't truly know if you are or are not aware of it!)
- It is difficult to use traditional assessments of pain and discomfort with people whose disabilities make communication difficult or who experience sensory differences. This is because their "language and signs of pain/discomfort" are likely to be different, too. For example, "ASD individuals may not present with the same symptoms or 'red flags' as their 'neurotypical' peers. Medical history may not help us. (And) many ASD persons cannot tell us if they are hurt/are uncomfortable nor accurately localize discomfort."


Dr. Margaret L. Bauuman

As a result, too many medical practitioners are unable to accurately diagnose and/or treat health issues affecting people with autism spectrum differences. Worse, unusual behaviors on the part of people with autism are too often interpreted as "part of their diagnosis" and dismissed rather than being viewed as possibly indicative of pain or discomfort warranting further diagnostic evaluation and treatment. Still worse, diagnosis and treatment of medical issues faced by people with ASDs needs to be multidisciplinary and integrative but systems to accomplish this are not widely available. Too many people with ASDs remain needlessly in pain or discomfort because of inadequate and/or inaccurate diagnosis and treatment.

The need for adequate and accurate diagnosis and treatment

Just like everyone else, people with autism spectrum differences need and deserve appropriate medical care. Dr. Bauman clearly made the point that ANY "changes in behavior or prolonged episodes of behavioral abnormalities merit a medical look." Further, many of the medical conditions leading to challenging behaviors are indeed medically treatable!

To facilitate accurate diagnosis and treatment, ALL associated medical concerns (e.g., "seizures, sleep disturbances, headaches, gastrointestinal disorders, genitourinary disorders (conditions such as "spastic bladder"), hormonal imbalance/endocrine dysfunction (a small subset of girls with ASDs have Congenital Adrenal Hyperplasia which can lead to high blood pressure or low blood sugar), and metabolic disorders (most commonly Complex I and Complex III electron transport chain disorders) need to be fully assessed. Other conditions such as neurological differences in the brain's centers of arousal, breathing problems, or sensory issues need to be considered.

Unfortunately, as Dr. Bauman explained, the presentation of such medical conditions in people with ASDs is often atypical, so traditional diagnostic tools may be ineffective and "the study is only as good as the person who interprets it."

Practitioners must know "red flags" and use alternative diagnostic strategies

For patients with ASDs, then, alternative assessment tools such as videotaping or magnetic imaging techniques may be required. Diagnosticians need to be aware of less common signs of disorders. For example, for gastrointestinal disorders these include "gulping and facial grimacing, tapping on the chest or stomach, putting pressure on the abdomen, (and) constant chewing on non-edible items…" Physicians must <u>not</u> attribute these types of behaviors to "they do it because they have autism." Genetic testing sometimes is helpful in making a diagnosis. As a specific example, Dr. Bauman noted that the MET gene is associated with both autism and chronic gastro-intestinal (GI) symptoms. It is not that either causes the other but that testing for the MET variance "may define a subset of ASD and co-occurring GI disorders." In other words, if there is an MET variance, maybe the challenging behavioral phenotype is caused by GI distress. Treat the distress and you eliminate the behavior(s) of concern.

It was heart-breaking to see images of the ulcerated esophagi of children whose difficulty sleeping had been attributed to "behavior problems" rather than excruciating pain secondary to severe gastric reflux. Advocates of alternative diets such as the most common gluten-free/casein free diet for individuals with autism have long spoken of the "mind-gut connection." Dr. Bauman pointed out how very true this is given that "every known neurotransmitter (ACTH, GABA, dopamine, serotonin) present in the brain is present in the gut" and has been shown to "affect GI motility and sensitivity in a variety of ways."

As another example, Dr. Bauman noted "red flags" signaling the need for a full metabolic work-up:

- "poor physical endurance" (excessive fatigue)
- late walking (i.e., after 24 months)
- repeated regressions after age 2.5 years
- dysmorphic features
- making poor progress despite excellent services
- qualitatively "different"
- involvement of multiple organ systems
- abnormal levels of blood lactate, blood alanine, and liver function studies

Although treatment for most metabolic conditions is in its infancy, knowing these are behind the behaviors of at least some individuals with ASD labels can prevent them from being inappropriately labeled as "behavior problems." Rather, these individuals deserve to be treated respectfully and kindly as one would anyone who has a chronically painful or uncomfortable medical condition.

The Autism Treatment Network

Dr. Bauman closed her presentation with information about the Autism Treatment Network (ATN) which was modeled after her LADDERS program. The ATN involves 15 sites associated with academic centers around the United States. Each site involves multidisciplinary medical teams and uses common protocols to more efficiently and effectively diagnose and treat medical problems experienced by people with ASDs. Participants in ATN conduct research to identify additional "red flags" that may be unique to people with ASDs, accurately identify medical problems, understand and apply effective interventions, and establish "scientifically sound and meaningful standards of care." Although ATN's contribution to science is significant, its most important focus for AutCom attendees is on improving the quality of life of individuals with ASDs so they feel physically better and healthier.

SAD DAYS IN MASSACHUSETTS

A bill to grant licenses to behavior specialists has passed the MA House of Representatives. its purpose to gain more power and dominate the field of services. Senate approval is expected.

MIT Lab Builds Electronics To Help Teach Students With ASD

by

Pat Edwards and Doug McClennen

(Special thanks to Pat Edwards for contributing to this report. As you will see, her program at Ashland University in Ohio made immediate use of the MIT Lab presentation.)

Dr. Matthew Goodwin, a postdoctoral fellow at Massachusetts Institute of Technology (MIT) in Cambridge, MA, demonstrated a series of innovative autism related technologies being developed at the MIT Media Lab: Wireless autonomic nervous system sensors, wearable physical activity sensors and computerized facial expression recognition systems. These technologies have the potential to enable non-autistic people to understand the ways in which autistic people are trying to communicate and to help individuals on the spectrum to understand their own and other people's emotional states. The purpose of these technologies is to improve social communication and regulation of emotions in persons on the autism spectrum (ASD). As Dr. Goodwin noted, the emotional and social difficulties experienced by many people on the spectrum lie at the core of ASD.

These problems can make interacting interpersonally loaded with stress and frustration. What may appear to neurotypical people as a decision to be disengaged or a lack of interest or even perception of others' communicative efforts is often actually only the outward result of ASD. Internally, persons on the spectrum may be struggling mightily with attempts to communicate and interact with others. Persons with ASD may have at their disposal only unusual methods of gaining attention, expressing wants and needs, and sending interpersonal messages. Use of symbols and nonverbal movements that are used to represent ideas differently than typically used are easily misinterpreted or even ignored by potential communicative partners.

The MIT Media Laboratory in collaboration with the Groden Center has developed wearable, social-emotional technology that helps individuals with ASD improve their overall social communication abilities. The lab is also developing technologies that build on the nonverbal communication that individuals on the autism spectrum are already using to express themselves socially and emotionally. This work will help families, educators and other persons who interact with those on the autism spectrum to better understand these alternative means of nonverbal communication.

Dr. Matthew Goodwin

Several other projects are also underway, including autism and emotional regulation, and sensor and toy technologies for monitoring children. Goodwin's graduate students accompanied him to AutCom 2009 and set up demonstrations of several types of wearable sensors and electronic communication sensors that will help educators who work with neurodiverse students to provide appropriate instructional strategies for the student's internal state and sensory-motor differences in communication.

As a result of this year's conference, Mish Madsen, one of Goodwin's MIT graduate students, has formed a partnership with Ashland University graduate student Nicole Teter. Madsen has traveled to Teter's Glen Oak High School classroom in Canton, Ohio, and provided sensors free of charge to two of Teter's students with ASD who do not speak. The devices were instantly accessible by Teter's students and Madsen explained the project to Teter's local and district administrators.

This long-distance collaboration to benefit students with autism illustrates clearly the potential impact of AutCom's annual conference on persons with autism, educators, and researchers.

Counseling People with Autism Using FC

by Thalia Vitikos, M.A., L.M.H.C.

Seven years ago I was in my office at the Wayside Metrowest Counseling Center in Framingham, Massachusetts, when I received a call from Rob's mother, Barbara Cutler. Barbara had been searching for a counselor for Rob. She told me about Rob's history, especially about the years he spent at Fernald State School during which time he was physically and verbally abused. She also told me that Rob was very intelligent and used facilitated communication (FC).

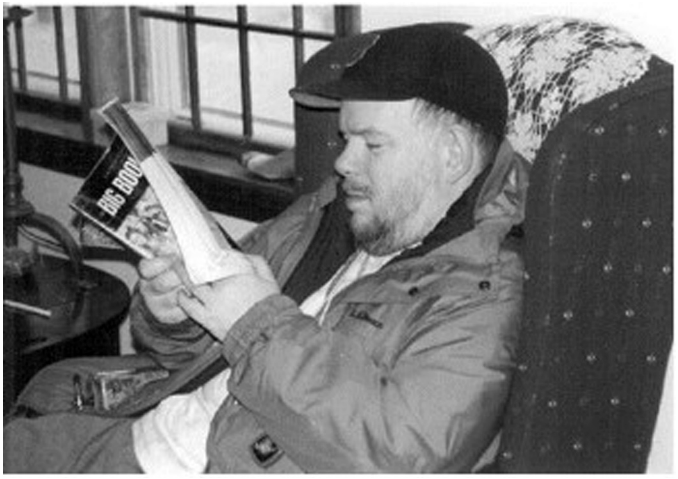
I have a Master's Degree in Expressive Arts Therapy from Lesley University in Cambridge. Because of my education and training in nonverbal therapies, such as music and art therapy, Wayside frequently asked me to evaluate and counsel people who were nonverbal or had limited verbal language skills.

I remember our first meeting well. Rob was very anxious and somewhat agitated because of an injury to his toes. He was unable to communicate either verbally or through FC. Rob presented the same way at our next session, so Barbara thought it best to delay the start of therapy.

I wanted to believe what Barbara had told me about Rob's intelligence and ability to communicate, but my first impression of Rob was anything but that. Because of Rob's inability to communicate and his overall behavioral presentation, I thought Rob was, at best, mildly mentally retarded, and that his family just couldn't accept that. And because of a previous experience I had had, which I will tell you about in a minute, I was doubtful that FC would work. Worse, I had been led to believe FC was a sham. Despite these initial impressions, I was committed to keeping an open mind.

A few months later, I received a call from Barbara telling me that Rob was ready to start therapy. This time Rob came with a facilitator, Michael Dowling, who was an accomplished artist and someone Rob trusted and had known for years. The FC was slow in the beginning, but it seemed to work, and Rob stayed with very neutral subjects which made sense. After all, Rob didn't know me.

I told you a minute ago that I had had a previous experience with FC. Prior to meeting Rob, I had been consulting to a progressive agency that had hired a trained facilitator to teach staff how to do FC with their ASD clients. The agency's speech therapist, who had an excellent reputation, had come to the conclusion that FC was fake. She said that the words on the paper belonged to the facilitator and not to the person with ASD. She showed me one person's type-written pages and said there was no way that [let's call him] Bob could have typed these words and phrases. So the agency never used FC again. That was my introduction to it.



Rob Cutler

As Rob typed with the support of Michael, I wondered whose words they were—Rob's or Michael's. But it became clear to me that each and every word was intentionally typed by Rob alone. I remember how genuinely surprised Michael looked at times by what Rob typed. When Rob changed to a different facilitator, Steven, the vocabulary, phraseology and subject matter remained the same. There was no doubt in my mind that Rob was the one and only author of the typed words. Later we moved to a letter board.

But what happened next turned my therapeutic world upside down. As I counseled Rob, he became an invaluable mentor to me. As Rob learned to trust me to help him heal from the trauma he had experienced, I learned I could trust Rob to answer my questions about what it is like to have an autism spectrum disorder. As Rob became naked and bared his wounds and scars to me, I became naked and bared my ignorance and self-doubt to him. I wasn't sure I could be a good therapist to him.

Rob, the consummate teacher with undying patience, taught me what it was like to live in his body, a body that wouldn't respond to his mental

(Continued on next page)

(Counseling People with Autism Using FC continued)

commands. Rob often "got stuck" in movements. He told me how stressful it was to have staff tell him to "hurry up" when he was stuck. People thought he was just trying to be difficult when in fact he had little, if any control. Rob explained why and how FC worked for him. He needed the energy and support from the facilitator in order for his thoughts to connect with his sensorimotor system so he could move his arm and finger. He told me that not anyone could be a facilitator. It had to be someone who was calm, unafraid and caring, and with whom Rob felt a connection.

And not anyone could be his therapist. It had to be someone who had empathy and cared about Rob. With Rob I lived what the research has shown: that the development and deepening of the therapeutic relationship is the most significant factor in successful therapy. The trust that develops allows for the transparency that is needed so that the person can tell their story.

Our relationship became and continues to be mutual which is not how many professionals define the therapeutic relationship. Traditionally, the therapist is considered "the expert" and the "client" is the recipient of this expertise. In fact, after seven years Rob and I think of each other as "friends" even though this is regarded as unprofessional and a violation of professional boundaries. But our relationship feels like a friendship because it is so caring and mutual—I counsel Rob and Rob mentors me. We observe boundaries because we want our relationship to continue to be effective. Rob wants to continue with his journey from pain and hurt to freedom, a journey that testifies to the strength and resilience of the human spirit.

Rob shared his life's journey through FC. He told a true story of mythic proportions about a human being who had been born into a body that couldn't do what he needed it to do because of neurosensory issues. Rob patiently described his experience in this body. And because this body couldn't move and speak "normally," Rob was never able to communicate and participate in the world with all its neurotypicals. He became increasingly isolated. He would occasionally lose control because his neurosensory system would become overwhelmed, and he had difficulty managing stress and anxiety. Because of his difficulties with maintaining control, he was placed at Fernald State School in Massachusetts.

Rob was then badly abused by a staff person who knew full well Rob couldn't tell anyone about the abuse. When his family figured out what was going on, they pulled him out of Fernald. By then, Rob had developed severe Post Traumatic Stress Disorder and was very angry by how he had been dehumanized and mistreated for "having done nothing wrong except be born with autism." What was worse for this kind and gentle man was that Rob knew people regarded him as threatening or "bad." Knowing Rob and how empathetic, compassionate and kind he is, I knew this was extremely painful for him.

For several years and through FC, Rob slowly healed from the injustice, indignity and humiliation he suffered as an autistic man who couldn't tell people what he needed to calm his neurosensory system so he could function in the neurotypical world. Counseling focused on the restoration of a sense of safety, trust, belonging, purpose and a core identity as a good, caring human being. Rob, the eternal pleaser, learned not to be afraid to express and assert himself. His progress has been amazing, and his story has a happy ending.

These days, Rob talks about his passage from dehumanization to freedom and joy. In this real story, the protagonist, Rob, conquers his demons and goes on to mentor real adolescents in South Boston who are struggling with their own demons, for Rob can relate. He is a much-needed source of strength and help to them. Rob has a great number of friends, as many of you know, and engages in many social and recreational activities. He loves to travel and is an avid camper. Rob participates in a weekly music therapy group. Music helps him relax. Quite a passage from confinement to freedom.

Finally, I learned not to assume I know what Rob is thinking or feeling. A lot of times when you think you know the answer, you will discover you are wrong. Rob is more than capable of telling others what he thinks, what he needs, wants, loves, dislikes, etc. There is no need to guess, especially if there is a facilitator around. And right now, that is what he needs—more caring and empathetic people to become facilitators. I would encourage people to do it. It could be the experience of a lifetime.

"I only hope that there are more caring and good therapists out there to help my friends. She needs to show the world we are humans who have been silenced long enough. Let our voices scream 'we are humans'. Yes!" says Robert Cutler.

Why Kids with Autism Today Need the Inclusive Education Denied Me

by Jacob Pratt

Kids with autism today are both entitled to and in need of the inclusive education denied me because I had severe autism. This meant my body was hard for me to control, my anxiety level was off the charts, I certainly couldn't use my voice to produce anything but echoed words, loud noises and babyish songs – all of which I still do today—and my sensory system was not providing me with the information I needed to function effectively in school. These differences plus the fact that I failed all the tests led everyone to assume I couldn't learn. So until my mother took my school district to due process to demand I be included in high school, I was segregated in self-contained classrooms where the cycle of perceived incompetence was perpetuated.

Today with what we know about autistic brains there is no excuse for thinking that failure to pass any standardized assessments tells anything about intelligence. I am familiar with Morton Ann Gernsbacher's work that shows that both kids and adults with autism do much better on certain kinds of tests while the scores of neurotypical people stay the same. I am not a researcher but it seems to me that this should raise more questions about the tests than about my intelligence. But as Jeff Strully says, it still shouldn't matter. Still, for those of us with autism, self-containment without peer role models and access to a rigorous academic curriculum plays into our autism and makes us less able to reach our potential as adults.

Here are some reasons why.

First is the little matter of us needing friends. All kids need friends. But if the only other kids around you at school are also those who have trouble making friends because of their own movement, anxiety, communication, and sensory differences, friendships just aren't going to happen.

Second is the matter of language and communication. If those of us with autism are only around others who recite film credits or say nothing at all, how are we to be motivated to communicate?

Third, with all due respect to special educators, I have never met one at the secondary level who had the right background to teach all subjects effectively. You may think I'm able to teach algebra or U.S. history just because I took it once, but I am not. People with autism need to be taught content by content experts just like everyone else who is a student.

Fourth, we know how to provide the reasonable accommodations someone with autism needs to be successful in general education classes. Some of us need more time to perform and alternative assignments. Some need facilitated communication support to show what we know. Some need regular sensory breaks to function. Some need a note taker. None of these are outlandish requests and all can be met with the existing resources in a public school and in general education classes.

So in summary, there are absolutely no excuses why kids with autism today should be denied the general education denied me. In fact, when you do, you exacerbate difficulties we have relating to the neurotypical world and the difficulties people in that world have understanding our neurodiversity and that inside we are not very different from them—except for the pain of constant ostracism AND THE SORROW OF ALWAYS FEELING MISUNDERSTOOD. WE OWE IT TO KIDS today to never ever let it happen like it did to kids in my generation.

Conference Impressions

(continued from first page)

Rather than go on for far longer than anyone would want to read, I will try to summarize, and of course that means I am running the risk of missing something important. My best advice—visit the website and make plans to attend the next conference, October 15–16, 2010, in Milwaukee, Wisconsin.

There were three very strong audio-visual presentations:

- “The Power of Words” - a stirring reminder that how we talk about people, ourselves and others, means a LOT. Mayer Shevin wrote the original “The Language of Us and Them.” and Judy Endow put together this powerful PowerPoint presentation, with music composed and played by her son, Daniel.
- An impressive and amusing travel documentary featuring two long-time FC users, Larry Bissonnette and Tracy Thresher, who recently traveled with a camera crew to Sri Lanka, Japan and Finland. Both of these amazing men have been typing for a long time now, currently needing little or no physical support – and both are starting to talk by reading what they have typed. It’s amazing!
- Another documentary in progress is the joint project of Rob Rooy and DJ Savarese. The segment we viewed showed a Readers Theater presentation written and directed by DJ, telling his life story and put on by his friends and peers at Grinnell High School in Iowa. That young man has talent and quite a story to tell!

Exciting news from the research field includes a study from MIT showing the high (but often hidden) levels of stress and anxiety that people with autism often experience. Matt Goodwin shared a new way to monitor these varying states of arousal using just a simple wristband to transmit the information. The costs are still far out of reach, but the potential is there for us to have a much better understanding of what might be going on inside.

Along similar lines, Dr. Margaret Bauman talked about exciting new developments at Massachusetts General Hospital, where she has been a pediatric neurologist working with people on the ASD spectrum so long that most of her former childhood patients are now adults. There’s a large grant now available to improve medical services for these adults, along with a new understanding that many of the behaviors we associate with autism usually, perhaps always, have a medical origin. Such issues as mitochondrial disorders, gastric reflux and other gastro-intestinal problems are getting looked at much more closely.

Jessica Butler reported on the use of restraints and seclusion with kids in school. I’m preaching to the choir here, but this reminds all of us that while we have come a long way toward inclusion, understanding and acceptance, we still have a very long way to go!

Alan Kurtz reminded us not to worry about the words “science” and “evidence-based” practices, but rather worry about those who use such terminology to promote their own self-interests. When new evidence is presented, those who are “stuck” in their own ideology often can’t change their theories to fit the evidence. Instead they tend to dismiss what is happening before them. It is time for a paradigm shift with regard to those who type to communicate!

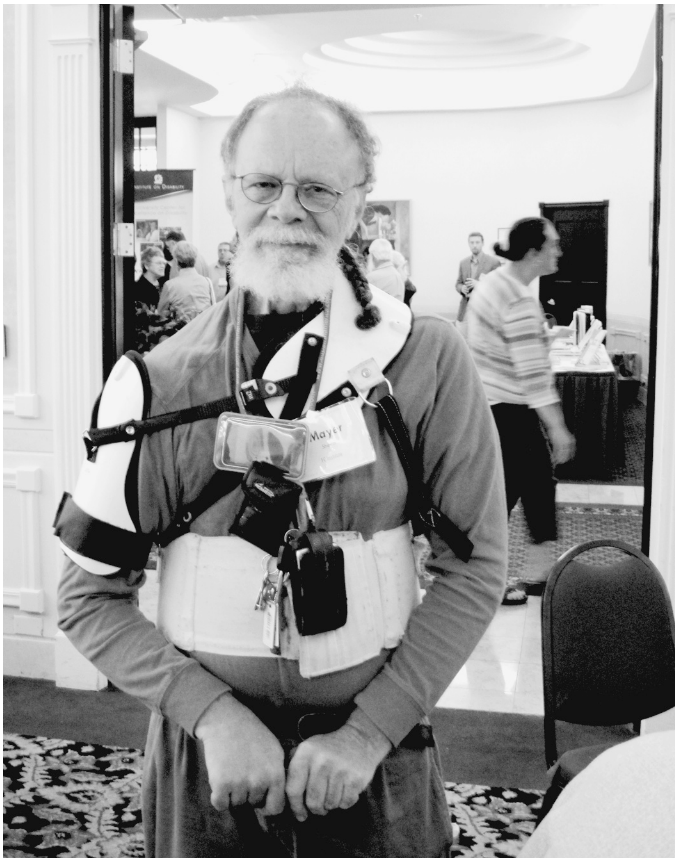
Many individuals gave presentations during the breakout sessions, telling their individual stories. It’s impossible to attend all of these sessions, and just as impossible to adequately tell their stories here. But I think it is safe to say in summary that people on the autism spectrum are taking charge of their own lives, and changing the minds and hearts of those around them. There is a unity among all of them (and those of us who love and support them) that has the power to change the world.

Judy Endow conversing with current AutCom President Sandi McClennen, about her presentation “The Power of Words.”

Scenes From the Conference

Alan Kurtz reminding us not to worry about the words "science" and "evidence-based" practices, but rather about those who use such terminology to promote their own self-interests

Tracy Thresher (with his facilitator Harvey Lavoy) presenting a documentary of his travels with Larry Bissonette, to whom we apologize for not succeeding in getting a good, accompanying photo. That's Phil Schwarz in the background.



Mayer Shevin, author of "The Language of Us and Them," on which Judy Endow based her presentation "The Power of Words"

The Silent Auction luring bidders

(More scenes from the conference on the next page)

More Scenes From the Conference

Ari Ne'eman presenting at his breakout session "The Autistic and Cross-Disability Communities"

Jeff Williamson and Nick Pentzell - "Living the Good Life: Creating Meaning Through Living"

DJ Savarese answering questions about his Readers Theatre presentation

Autism Holiday Wish List

This list was created by AutCom's Past President, Anne Carpenter, a woman with autism. This list first appeared in the November/December 1996 issue of ASM's Horizons Newsletter. Some wishes don't need to change.

My wishes are...

- To have freedom from being trapped by a label.
- That full inclusion in a regular classroom will be with caring teachers and trained paraprofessionals who can help a child reach her/his highest potential.
- That employers will give a person with autism a job and will accommodate that person and focus on that person's strengths.
- For safe, non-punitive early intervention.
- For treatments that are safe, inexpensive and will help people with autism live full meaningful lives.
- For people to recognize autism as a condition, or difference, rather than a disease and to think of our brains as being flexible and having infinite potential.
- To have all the light, sound and music toys anyone could ever want!
- For those with autism to have a quiet place to calm down when over-stimulated at any place, anytime, whenever one needs it.
- For chances to be one's own self without having to be "normal".
- To have the chance to wear soft, comfortable clothing, without belts, tight waistbands or scratchy wool on any occasion, even for formal events such as weddings, funerals or Bar Mitzvahs.
- To have opportunities to exercise, run, jump, and let off steam when one needs to.
- For a way to "use the brain to manage the brain" so we can stop, start, continue, switch and combine movement, behavior, thought, and emotion at will, at any time, whenever needed.
- For those with autism to have freedom from the "chemical straightjacket" of too many medications or the wrong medication.
- To abandon the assumption of "mental impairment" from the autism vocabulary.
- To let people with autism be whatever they want to be, abandoning the limited career slots such as jobs in the arena of "Food, Filth, and Flowers".
- For all of those individuals with autism to have a meaningful life with dignity and respect, including the opportunity to work, marry, have children, travel to exotic places, be an astronaut, brain surgeon, U.S. Presiden–whatever suits one's fancy!

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

Autism National Committee
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www.autcom.org

Time to Renew or Join Today!

Annual membership begins in January

Membership form on page 15

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:

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