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THE COMMUNICATOR

A Publication of the Autism National Committee



Honoring People with Autism

by

Barbara Cutler and Gail Gillingham

AutCom returned to Nashua, New Hampshire, for this year's conference on a glorious New England weekend in September. The conference, as usual, was attended by a mixture of parents and other family members, professionals and people on the autism spectrum (who accounted for over 20% of the participants).

The conference opened on Friday evening with the Academy award nominated film, "Autism is a World," introduced by producer Doug Biklen. At the close of this inspiring film, its author, Sue Rubin (right), answered questions from the audience.

Saturday was filled with many presentations on subjects of concern to those with autism and their supporters. Keynote presenter Dr. Martha Herbert of the Harvard Medical School began by focusing on the possible influence of assaults from the environment on autism. In a second keynote later in the day, Dr. Ruth Ryan Myers from Grafton, Virginia, addressed the need for better care and diagnosis of medical conditions not specific to autism, which require the same type of medical care available to the general public.



Sue Rubin and Emily Neimeyer

One of the most unique features of an AutCom conference is the opportunity to hear so many people on the spectrum share their life experiences. Over a dozen speakers with ASD made presentations on topics as diverse as higher education, how facilitated communication changes lives, art, and self-advocacy. Another award winning film, "My Classic Life as an Artist," was shared by Larry Bissonette (see photo on page 2). The twenty-two authors of AutCom's book, Sharing Our Wisdom, edited by Gillingham and McClennen,

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Honoring People with Autism

were honored for their gifts to the world.

Judith Bluestone of the Handle Institute delighted her listeners with a hands-on demonstration of her efficient methods for reducing anxiety on one young member of the audience during her presentation on the Handle method. Michael McSheenan of UNH spoke on the importance of communication supports for successful inclusion in schools.

The conference closed with "The Last Word," when AutCom Board members with autism reminded us of the important lessons we learned in our time together. An example of inclusion sent us on our way as one of our younger members, Natalie Williams, joined with her general education classmates via video in a heartwarming rendition of the song, "Never Give Up."

Jim Butler, father of a young son with autism, was a first time attendee of an AutCom conference. He shared his experience with us in this way: "The conference was one of the most inspiring and galvanizing things I've experienced in recent years, and probably ever. It's hard for me to put into words what I'm sure those who have been around the block a few times know all too well: the searing power of seeing how much progress has been made, and yet how much remains to be done. The door is open, but just a crack, and much more effort is needed to spread the light of greater understanding. I certainly felt the 'glow' in those who have been doing enlightened autism advocacy for a while now."

If you missed the opportunity to attend this conference, you will be glad to know that



Larry Bissonette, movie star and artist.

AutCom will be returning to Nashua next fall on September 8-9, 2006, so mark your calendar now. Our focus will be on the various ways that people with ASD can be supported by listening to the people themselves express their true needs. Our goal is to take over the whole hotel. Please join us!

"If you will accept me for wherever I am, all my energies and desires to grow will be released and energized. If you will reassure me that it is all right to be where I am now, I will have courage to move beyond where I am. With your loving acceptance of me, I will gradually grow into the fullness of life."

John Powell

THE COMMUNICATOR is a publication of the Autism National Committee, Inc., a 501 (c)(3) charitable organization founded in 1990 to protect and advance the civil rights of people with Autism/Pervasive Developmental Disorder and related disorders of communication and behavior. Contributions of articles, information and letters are welcomed. The Communicator does not carry advertising or fund raising announcements, and we reserve the right to edit all submissions. Your comments are actively sought. Send them to Gail Gillingham at PO Box 11245, Main Post Office, Edmonton, Alberta, T5J 3K5, Canada. THE COMMUNICATOR may be copied in its entirety or individual articles reprinted without permission except when otherwise noted. Please credit them to the Autism National Committee.

Thanks to Our Supporters

The Autism National Committee would like to offer our sincere appreciation to the organizations and individuals who sponsored and contributed to our conference, Honoring People with Autism, on September 9 and 10, 2005, in Nashua, New Hampshire. We couldn't have done it without your support. Thanks so very much!

Thanks to the organizations who lent their names to support the conference:

Northeast Regional Conference on Autism
University of New Hampshire Institute on Disability
Massachusetts Developmental Disabilities Council
Vermont Developmental Disabilities Council
Vermont University Center of Excellence
Jay Nolan Community Services
TASH

Thanks to the contributors who supported the participation of individuals with autism:

Northeast Regional Conference on Autism
Vermont Developmental Disabilities Council
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It's That Time Again!

January is just around the corner and with the new year comes membership renewal time for AutCom. Please complete the membership form at the back of the newsletter and mail it to Wade as soon as possible.

Need a reason to join? New board member Jenn Seybert says it this way: "I want to be a part of the growing awareness of AutCom. This organization is truly one of the few who are active in promoting the issues—learning, developing, and caring—that are truly important for autistic individuals. I would like to accomplish something that is dear to my heart: an increased public acceptance of autistics as valuable, contributing members of our American society."

The role of this organization is to continually seek and disseminate the best information available to families and professionals. Without this key component, AutCom would not be what it is today. Because of AutCom's tireless activity to make correct information about the issues of autism visible and relevant, autistic individuals are listened to and respected. They are also among the more vulnerable individuals in our society. Without AutCom's activism, we could easily lose much of the political, social, and medical gains made in the last decade.

Your membership and support are necessary for keeping AutCom active!

Thoughts on Being the AutCom President

by Anne Carpenter

For the last few years as Vice-President of the Autism National Committee, my desire to play a greater role in the organization grew stronger as I learned more about the activities in which AutCom is involved and as I became aware of distressing news about the use of restraints and harmful, inappropriate treatments done to children on the autism spectrum, many of them African-American. When I was elected, at first I wondered just how I was going to do this. Then I felt a rush of excitement—now, I have that golden opportunity to really steer this wonderful organization into an even more positive direction. By strengthening an already wonderful organization, we can develop an even better AutCom.

Rather than thinking of myself as being in a position of power, I think of myself as being in a leadership position, as a guiding light, to shepherd the other AutCom members and to guide them through the year with advice, counsel, and creative, compassionate ideas that can foster a much more positive view of Autism Spectrum Disorders than we are currently experiencing. This will be no small task, as this negative attitude and the quest for "cure" and "recovery" permeates every fabric of our society. This is fueled by several factors, including continued scientific research into the causes and mechanisms of autism, well-founded concerns about toxins in the environment, funding cuts in education and social programs, resulting in a desire for a more "normal" population, and confusion about the nature of the autism spectrum itself.

The best way to go about this mission is to continually chip away, little by little, at the negativity surrounding Autism Spectrum Disorder by coming up with ideas and solutions that emphasize the person's strengths and competence and value as an individual and by finding ways to redesign society, so that individuals on the spectrum can grow, flourish, and become the extraordinary human beings that they are.



Anne presides over her first AutCom Board meeting as President in Nashua with board member Larry Bissonette in the background

The potential is vast, unlimited, and right at our fingertips. But we must go about tapping into the fund of unlimited potential, right here, right NOW. As President of the Autism National Committee, I know I can't do everything, but I can lead the way and help others to start to institute real change, however slow and difficult this process may be.

ASK ROB

by Rob Cutler

Q: What role has faith played in your survival as a person with autism?

A: I believe in a higher power called God. I want to type about good things God does for me. He protects me when the evil memories of past creep up in my mind. He provides the ocean sounds which man recorded on audio tape so I can sleep at night. God in His time provides rain and snow which clean the air so I can breathe better.

God was always there [in the institution]. I value God because He never left me while behaviorists tried to mess me up with restraints and nonsense. God speaks of kindness and love while mankind uses autism to make money preaching pain and aversives.

Man cannot accept one idea let alone ten written in stone.

I believe there are many forms which God

took in order to save humanity - Buddha, Allah, Jesus, to name a few. I am of a faith which believes God is in charge but autistic people are sitting at His table. I feel God is with all children and adults with autism. We are valued by God.

I survived and move forward because I am loved, understood and supported. I know God planned this for me, yes. God loves when parents fight for their children. I want parents to accept our autism and learn how to communicate to us through FC. Keep trying.

Never give up hope.

How do we return to basic thinking of religion? Remember the movie, "Angels in the Outfield"? The woman said if a player gets down and thanks God on one knee for scoring a touchdown or a baseball player crosses his chest to thank God for a winning hit, these are God in simplest terms.

Churches are nice but God is outside and in our hearts. God is neither Democrat nor Republican, thank Him, yes.

New Board Members

The Autism National Committee would like to introduce the new members who joined our Board at the conference in Nashua. We look forward to working with them in the coming years.

Zach Rossetti, M.Ed., is currently studying as a doctoral candidate at Syracuse University, where his research interests focus on school inclusion and friendships between students with and without labels of autism and other developmental disabilities. He hopes his work will yield specific strategies of inclusive pedagogy that can help individuals and groups achieve the elusive ideals of school and community inclusion. Zach has a M.Ed. in special education from the University of New Hampshire and is the co-producer and co-director of the film, My Classic Life as an Artist: A Portrait of Larry Bissonette (2005). He believes that creating documentary films in which individuals with autism labels can tell their stories and share their experiences rather than being objectified and talked about is one of the most effective ways to "lop off weak branches of disability."

Jenn Seybert is a young woman on the autism spectrum who will graduate with a B.A. in Psychology from LeMoyne College in May, 2006. During the past ten years, she has presented seminars and workshops on facilitated communication, person-centered planning, self determination and humor to a variety of professional and lay groups

in Pennsylvania, New York, and in England.

Her experience includes counseling non-speaking autistic people at the Facilitated Communication Institute at Syracuse University and mentoring self-advocates through New York's Office of Mental Retardation and Developmental Disabilities. You can read more about Jenn in her chapter, "Inclusion...Finally!" in our book, Sharing Our Wisdom.

Mary Clare Schuh, Ph.D., is the Associate Director of University of New Hampshire's Institute on Disability and a research professor in the Department of Education. Her work in the area of autism includes the development of a new Center of Excellence, the New Hampshire Center for Autism Resources at UNH, the coordination of a professional development Research-to-Practice Series on the topic of autism, and a member of the NH FC Policy Task Force which oversees the Communication Skill Builders Group for individuals who use alternative methods to express themselves. She is interested in AutCom because the leadership of the organization represents the most "cutting edge" thinkers in the field, and she hopes to learn through her participation.

Gail Gillingham, M.S. and Douglas Biklen, Ph.D. have agreed to return to the Board for their second 3-year term. Our Board now has 25 members, our legal limit.

Thumbs Up!

by Gail Gillingham

Thumbs up: a quick review of some of the good news happening in the world of autism

THUMBS UP to Exceptional Parent Magazine, which has taken a stand against aversives and restraints. Their position statement goes further than simply stating opposition to the use of aversives and restraints. They will demonstrate their commitment by not accepting advertisements, sponsorships nor support by any organization, group school, camp, residential facility or association that employs the use of these methods. Consider expressing your support directly to EP magazine (you can send comments to Rick Rader, EP's Editor, at habctrmd@aol.com and/or subscribe to EP as a way of showing your approve of this courageous move).

THUMBS UP to Kenny Affonce (photo right) and his support team for helping him regain his voice. Kenny wrote the chapter, "Dare to Dream a Little Dream," in our book, *Sharing Our Wisdom*. Readers may know that Kenny was no longer typing after the death of his father. We were thrilled to see Kenny back at the keyboard at the conference in Nashua and to thereby have the opportunity to converse with him again. We hope this means that other of his dreams will come true in the coming years.

THUMBS UP to the Vermont International Film Festival for awarding "My Classic Life as an Artist: A Portrait of Larry Bissonnette," directed by Douglas Biklen and Zach Rossetti, as the best short film in the Festival. This is what they said about the selection process: "In the category of Short Films, the films in competition this year were truly amazing. It was very difficult to choose among such a diverse and accomplished display. In truth, they are all winners. But choose we did. Our selection for Best Short Film in the Festival goes to a moving portrayal of the great gifts liberated in an individual when family and society combine to support those who are differently abled. It is an outcry against the labeling, prejudice and stigmatization that rob human beings of their dignity and autonomy. It is an outcry against involuntary incarceration and marginalization that has gone on and still goes on due to the ignorance of the 'experts'. We are all thrilled to see the truly inspiring art and extraordinarily poetic gift for self-expression displayed by the hero of our winning film." Congratulation to Larry, Doug and

Zach—all AutCom Board members.

THUMBS UP to the Massachusetts State Legislators who are working on a bill for the 2005-06 session that would ban painful aversive therapies, including electric shock, that are still being used by a small number of agencies contracted with the state to provide services to people with disabilities. In recent years, effective alternatives have been developed and used to address the type of self-injurious behavior for which aversive therapy is primarily used as a treatment. Aversive therapy advocates tout its use as a "last resort" for people for whom they see no alternative methods of treatment. Their view



Kenny Affonce, one of the authors of *Sharing Our Wisdom*, speaks to us via the keyboard in Nashua in September.

has been universally condemned by mainstream disability, advocacy, civil liberty and legal rights groups who believe the treatment to be a barbaric form of behavioral control. In fact, the ethics of aversives would likely generate public outcry if administered to animals, yet aversives remain legal when used upon human beings in Massachusetts. Citizens of Massachusetts, please contact your legislative representatives to ensure the passage of this bill.

THUMBS UP to Syracuse University in New York for appointing Douglas Biklen, Ph.D., to the position of Dean of Education. Doug has been a determined and dedicated advocate for the full inclusion of those with disabilities throughout his career. He is also well known for introducing facilitated communication to America and helping establish the Facilitated Communication Institute

at Syracuse. His belief in inclusion will continue to influence all educators trained at Syracuse University.

THUMBS UP to WOW and the State of Colorado who have decided that it is worthwhile to invest time, energy and money into training people in facilitated communication. AutCom Board member Mike Hoover is a founding member of Watch Our Words Colorado (WOW), established three years ago as a way for facilitated communication users to get together and have discussions. Last year, the group of eight decided they wanted to do more than talk, so Hoover applied for a \$25,000 grant from the Colorado Developmental Disabilities Council. That money has enabled WOW to host four training sessions over the past year. Way to go!



Mike Hoover with his mother, Donna Downing

Principles of the Autism National Committee

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

Moreover, I oppose the use of institutions to separate people from their communities, and deprive them of dignity, freedom and the level of independence they can achieve in supportive community living; the use of procedures involving pain, humiliation, deprivation, and dangerous drugs as a means

to alter and control individual's behavior; the increasing use of bizarre technology to control self-injurious and aggressive behavior; the widespread ignorance of the basic social and communicative needs of people with autism; and the widespread disregard for the individual's unique, basic and human needs. I object to programs which disregard the skills, preferences and basic human needs of the people they serve, and I believe that there is no longer need or any justification for using painful and abusive procedures.

AutCom Officers and Chairpersons

Anne Carpenter, M.S., *President*
 Margo Williams, *Vice-President*
 Anne Bakeman, *Secretary*
 Wade Hitzing, Ph.D., *Treasurer*
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The COMMUNICATOR Committee

Alan Kurtz, M.Ed.
 Barbara Cutler, Ph.D.
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www.autcom.org



Time to Renew or Join Today!
Annual membership begins in January



MEMBERSHIP FORM

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

JOIN NOW

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NAME _____

ADDRESS _____

CITY, STATE, ZIP _____

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E-MAIL _____

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

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

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

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**Autism National Committee
Wade Hitzing, Treasurer
1045 Wittman Drive
Fort Myers, FL, 33919**

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