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THE COMMUNICATOR

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Embracing the Hope and Joy of Autism

The 2008 AutCom Conference was held in Ann Arbor, Michigan, on October 17 - 18. Attendance was outstanding, with more than 200 people from Michigan, the rest of the U.S. and Canada. On Friday, Paula Kluth, Anne Donnellan, Martha Leary, David Hill and Sharisa Kochmeister conducted an all-day workshop: *Getting beyond "Behavior" - Including and Supporting ASD Individuals in Home, School and Community*. Friday evening, Johnny and Chris Seitz gave us a beautiful mime performance, "God Does Not Make Garbage," with a discussion afterward.

Saturday's presentations included panels on a wide range of subjects. Jenn Seybert coordinated and led the panel, "Our Bachelor's Degrees Are on the Wall, but Our Journeys Are Far from Over," whose other participants were Ian Wetherbee and Sean Sokler. Their presentations are featured in this issue, as is Rob Cutler's. Other panels and presenters:

- "A Little Experience Often Upsets a Lot of Theory: Stereotypes about Disability" - Amanda Baggs, Nick Pentzell, Kassiane Sibley & Sharisa Kochmeister
- "Living a Healthy Life with Autism" - Mike Hoover & Rob Cutler
- "Maximizing the Communication Potential of Facilitated Communication Users" - Pascal Cheng, Larry Bissonette, Tracy Thresher & Harvey Lavoy
- "Friendships, Dating and Relationships" - Anne Carpenter, Ian Sterret, and Johnny & Chris Seitz



Chris & Johnny Seitz

- "Neurodiversity: Views from Those of Us Who Are Supposedly Neurologically Atypical" - Jacob Pratt, Jamie Burke, Daniel McConnell & Ari Ne'eman
 - "Life and School As a Teen on the Spectrum" - Alex Kimmel, Michael Matthews, Dylan Russell, Krista Shuler, and Andrew Ackner
 - "Parenting on the Spectrum" - Jim Butler, Jay Kochmeister, Phil Schwartz & Paulette Wyman
- Future issues will feature other presentations.

Save This Date!
AutCom 2009 Conference
September 25 – 26
Nashua, New Hampshire
Crowne Plaza Hotel

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Web Site: www.autcom.org

Our Bachelor's Degrees Are On the Wall, But Our Journeys Are Far from Over

Jenn Seybert

Le Moyne College
B.A. (Psychology), 2006

It has been one hell of a journey with many twists and turns and ups and downs. I sat for 24 years in silence not being able to be understood or be heard. The rage and frustration is too hard to share.

I sat in self-contained classrooms except for specials as adaptive phys-ed, music, art and assemblies. The whole time I was in school, there were minimal academics taught. The mind-set was no inclusion in any area of the school setting, and we were spoken to in a condescending manner. After all, our I.Q. showed we were retarded and simple. For the most part, my teachers were lovely, but there were a few I wish would have dropped off the face of the earth.

You can see a pattern evolving here, just time spent doing very little, with no one listening or questioning the frustration. Then, after 21 years being in the system, I graduated with my neuro-typic peers. What a great feeling I had with this experience, but this feeling was shared with emptiness inside knowing I was not a partner in this graduation, only in a bodily sense.

I wanted more. I wanted what they had. I wanted to have an education and decided that night that somehow I was going have this.

As the weeks moved on, my peers sought employment or went off to college. I went to a workshop to put paint sets together, stack cups and other mundane trivia. At least I had the education to back this venture! I was retarded and this was my life!

I was fortunate to be freed from the world of retardation on July 18, 1995, when I was evaluated for Facilitated Communication (FC). Not only the label of being retarded was removed, the label of having intelligence was attached. My life was open from the dark hell I was attached to and the opportunity this miracle gave me, and is still giving me, is overwhelming.

It took about a year before I was ready to move on. I had, along with my family, many adjustments to adapt to in my new circumstances. Trust played a very important role here, and trust was and still is a hard lesson to learn.



Jenn Seybert with her mother, Kendall

The next step in my life was to develop a life. A new dear and trusted friend stepped in and taught me the way to respond to accessing my dreams by helping me sort my thoughts so I could set goals and master them. This is called Person Centered Planning and is a process as you strive to become self-determined. This process for me allowed me to pull away from the dark hole of autism and realize I could have a more enriched life. Regardless of the positive end results staring at me, it still became a struggle of emotions as I evolved.

I wished to meet others who used augmentative communication as I, so The Lonesome Doves were born. I wanted to seek my life-long dream of going to college, and that became a reality as I entered Penn State University, taking one course at a time until I was ready to add another and another. I was able to carry 9 credits each semester and still keep a 3.0 or better.

In 2001, my father accepted a new position in Central New York, and I chose to move with my parents. I transferred 33 credits from PSU to Le Moyne College in Syracuse where I graduated in May, 2006, with honors. That fall I applied all my graduation monetary gifts and took my first graduate class.

I wanted to continue with my education but was not sure what avenue to proceed on. After my graduate course was over, I realized I needed time to figure out my next step.

I was accepted into New York State Partners in Policymaking Training in March, 2007. This commitment was for eight months. I graduated from

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there in November, 2007. I found the information valuable and applicable to my current journey.

Following are some of the "happenings" that have occurred in my life that I want to share with you.

I am active in the community. In October, 2006, I attended a Community Leadership Retreat and represented the Central New York Self-Advocates. I continue to serve on the Community Participation Steering Committee through the Central New York Office of Mental Retardation/Developmental Disability Office.

I have been published in books and journals. I have given presentations in many states and in Bolton, Manchester and Liverpool, England. I am a member of the Board of Directors of the **Autism National Committee (AutCom)**; an Associate of **Networks for Training and Development**, and with **The New York State Disability Advocacy Association and Network**.

On March 24, 2007, I took the step of typing independently, with only a light touch on the back of my elbow for support. I love the freedom it gives me but draw back because the hard tug from the autism within keeps trying to pull me back inside, not allowing me the feeling of total excitement. My support is growing less as my facilitator is lightly touching the top of my arm for feedback. I will type independently.

Being involved in community activities near and afar, there was a piece of me that was empty. I still felt the need to continue my education. I was so bored at home. I began to explore different programs online and locally and chose to apply to Syracuse University in their Masters program of Disability Studies. While waiting to hear, Le Moyne College offered me an acceptance in their Education Department for a Masters in General Education. I was very touched by this, but in the end I didn't know where I could seek employment.

In January, 2008, I registered for my first SU graduate course. I felt it would be wise to familiarize myself with a much larger university compared to the small college I came from. I was overwhelmed at first because there is a vast difference between graduate school and undergraduate school.

Finally **the letter** I was hoping to receive arrived this past February! I was accepted into the Masters Program in Disability Studies at Syracuse University for this fall's term!

I work hard and read several hundred pages of

assignments a week depending on the class. I have bloodshot eyes and am sleep-deprived depending on the week. When the griping is done, I am having a great time. We have brown bag lunches with fascinating speakers. I have joined the group called **Beyond Compliance** that concerns itself with looking after students with disabilities on campus, arranging for speakers for brown bag lunches, and setting up movie nights with a disability genre. There are also great get-togethers at The Incomplete. There, wine comes in red or white, beer comes in thirteen different brands. The food is great if you like hot, spicy and fried.

One of the privileges of being a grad student, I have been invited to sit with the **Facilitated Communication Institute (FCI)** and be a part of the planning committee, along with other grad students, for various events happening on campus.

From the time I was able to communicate, the driven feeling I had was to reach out and share what I could about autism. I have also worked with individuals and families to help these folks with their issues and for family members to develop a greater understanding and insight into the world of autism.

The field of Disability Studies is exactly the way I wish to follow my pursuit in developing skills and information to guide, direct, listen and become someone for those in the area of disabilities to rely on. My Bachelor degree is in Psychology and has provided me a solid base on which to now build. Herb Lovett has had a profound effect on me. I plan to continue to follow his legacy throughout my career.

**2009 Institute on Disability
Autism Summer Institute
August 10-13, Holloway Commons, University
of New Hampshire, Durham, NH**

This year's Summer Institute will provide both parents and educators with evidence-based practices for supporting students with autism spectrum disorders in the general education classroom.

Questions about this or other workshops? Visit the IOD online at www.iod.unh.edu, call 603.228.2084, or e-mail contact.iod@unh.edu.

Our Bachelor's Degrees Are On the Wall, But Our Journeys Are Far from Over

Sean D. Sokler

George Mason University

B.A., 2005

Editor's note: Sean's presentation used PowerPoint and included illustrations. We have edited (with his permission) to give you (in his own words) the important points he made.

What now? I did not know. I thought about what I wanted to do but could not come up with a solution. There were so many jobs I could not do. I had no role models, no "parachutes" and I felt I needed to Look for a job. No "parachutes" means I felt I did not have a safety net if I failed to come up with something good to do.

In May of 2005, I knew of only one person who had graduated from a four-year university program with a diploma and who had used facilitated communication: Sharisa Joy Kochmeister, Autcom's President. Thus, I knew nothing of what others did if they had autism and the diploma.

Why It Isn't Easy for Me to Find a Job

My Abilities re: Work

I can write clearly and without spelling errors.
I have a high I.Q.
I can read and analyze text.
I can type, but with one index finger stroke at a time.
I know AP Style (journalism's manual).
I am fluent in writing in Spanish, French and Italian.

My Disabilities re: Work

I need a personal assistant to support my typing.
I have poor fine motor skills.
I have a bad habit of staring at pages of magazines.
I need flexible hours due to needing extra time to get ready to go out.
I am a notorious flirt.

What Job Could I Do Well?

(Remember - I can only speak sentences reliably with facilitated communication, and my fine motor skills are not very good.)

- Construction worker building a hydroelectric dam? No!



Sean Sokler and his mother, Barbara Cunningham

- Farmer? No!
- Rodeo cowboy? Are you kidding?
- Chef? I don't think so.
- Oh, my! Not many jobs he can do!!

What Do You Do After Receiving Your Diploma When You Have Dyspraxia and Autism?

I had hundreds of ideas about what to do after I graduated from George Mason University. Getting to do them was difficult. Some I achieved, and those went well:

- Presenting at conferences
- Demonstrating facilitated communication in Spain and France

I had no time limits put upon me to achieve anything. Six years of study, a major in Psychology and a minor in History had left me and my family needing a hiatus. . . recreation. . . a time to relax. But I had to think. . . even while doing "nothing." I was lucky in that my family did not force me into a job. What can you do when you have a university education and no job prospects? Relax and think of the future !!!

Go to Conferences

Harvey Lavoy, III, and I went to the 2006 Autcom Conference in Nashua, New Hampshire. I typed with Harvey on my Neo, an upgrade from the AlphaSmart. I needed support at the wrist to type—that is part of my dyspraxia. I typed using facilitated

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communication.

I went with Dr. Toby Long to Georgetown's conference on young children and autism. She wanted me to show a group of doctors, therapists and Washington, D.C. public school teachers of students with autism what a person with autism can achieve.

I started presenting in 2000, but after I had graduated, I eagerly went forward. I presented "Heaven is George Mason University" at Autcom 2005, Georgetown University's Autism conference in 2006, TASH in Milwaukee in 2006, Autcom 2007 in Alberta, then at Radford University and at I.S.A.A.C. in Montreal, in 2008.

Spend Time with the Family

- Go to the pool with Dad
- Lounge (I am very good at lounging)
- Travel

What do I want to do? What should I try to do for a career?

In between lunches, lounging and travel, for which I am grateful, I was always thinking. I decided to take courses in writing and journalism. If I could learn to write a good newspaper or magazine article, perhaps I could further the progress of those who have autism and other significant disabilities who would like to have freedom from institutions and group homes and silence. Everyone deserves a home and a means of fluent communication. I also want to write about accessibility of some of the major tourist sites. My experiences in Europe and the Galapagos have shown me that not everyone is ready to adapt.

I'll be good at online journalism because it does not require much fine motor. Perfect. Just give me these: a laptop, a Neo, a USB cord, AC power cord, electricity, an adaptor, plus an internet connection, and I'll report on life at Lake Garda, Italy, both its grand views and its inaccessibility for persons with significant disabilities.

Here are a few places to look when one searches for a job, and one has disabilities:

- First go to Dale DiLeo's Site: www.daledileo.com. Look at the news mpg. In the center column of page one of his website, Dr. DiLeo states that unemployment levels for persons with disabilities are at 70%.

- Second, try this website: www.peoplresources.org/employment/employment.htm. Their motto is "Advancing The Success Of People With All Types Of Disabilities."
- The following website is very good for finding a job IF you live in an area where there are jobs. www.freecareersearch.com. The career search is free.

Also read the following article:

[Employing persons with severe disabilities: Much Work Remains to be Done.](#) Kennedy, R. Bryan, Harris, Nicole K.

[Journal of Employment Counseling](#) Date: Thursday, September 1, 2005

Excellent article.

Thank you for listening and watching. It is a long road to finding a career but well worth the time and effort on your part.

Ian Wetherbee

Huntington University

B.A. (Communications), 2004

Editor's note: Ian began his presentation with a glimpse of his college years in the form of excerpts from his columns, letters and presentations written while he was at college. You can learn more about Ian's experiences in college by going to his web site and blog at ianwetherbee.com. You can email Ian at iwetherbee@comcast.net. Having given us a glimpse of his experiences at Huntington College, Ian brought us up-to-date regarding life after graduation.

And Now Back To Today

Mostly, I don't use my education. OK, I do view my life as richer for having gone to college. My self esteem is higher and I can listen to a math lecture and not get lost. False statements made around me are less likely to mislead me, and I am fairly well read. I have found friends while going to class and have been in good discussions even if I mostly listened. I have walked across the platform and shaken hands with the University's president and been handed my diploma. I loved going to college! But one day it was over and done with.

In truth, it was a long seven year journey that my family and my facilitators and I had completed. Even before that, it took me five long years to

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complete high school. One hour of course work represented tens of hours of cooperative effort by me and my support group. Before I had finished, I had gone through many facilitators, not counting my dad. I had written close to a hundred columns for the University newspaper, and I had been quite busy almost every evening during each school year doing homework. My dad facilitated with me during almost every minute of work that I did on those evenings. When I changed facilitators and the learning curve was in progress for the new facilitator to learn to get my words correctly, Dad also facilitated my tests. On graduation day, we all collapsed in relief. The pressure was off.

That was four years ago. Since then, the pace of life has slowed considerably. My brother Todd helped me begin a website and a blog. I have written some articles for autism related newsletters, and I have written two alumni profiles for the Huntington University website. This past year I audited a Discrete Math class at Huntington University. If you had told me at a time before I could use FC that I would someday be able to do these things, I would never have believed you. Now I find this amount of intellectual activity to be somewhat disappointing, given my educational accomplishments.

What has been our problem? It has been a



Left to right, Win & Ian Wetherbee, Jenn & Kendall Seybert

combination of things. At first, everyone involved in my college studies sort of collapsed with relief when I finally graduated. I was now free of my hours of studying and making my thoughts known through FC as I wrote papers and took exams. A great load of work and responsibility was lifted from the shoulders of my Dad and Mom. I and my facilitator could spend our days doing fun and relaxing activities. We all needed to find some relief and we did.

I hoped to do some free lance writing. I had some pieces ready to submit for publication, but

WHEN THE SUN COMES UP Sharisa Joy Kochmeister, President of AutCom

When the sun comes up on this New Year
Will we go on living in endless fear
That the world's end must be coming soon
If we keep on playing this morbid tune
Of war and hatred so unbound
That no peace and love are to be found
In any corner of this place
That is home to our angry human race?

We pollute our skies, our land, our water
And the minds of every son and daughter
With hate crimes, violence and abuse,
Homelessness, hunger and misuse
Of all our planet has to offer
Blindly draining every coffer
Of any way to stop the sorrow
Leading towards a void tomorrow.

Why haven't we learned in generations
The importance of saving and conservation
Of resources drawing close to gone
Did we really think they would go on
Or replenish themselves from hidden wells
As we spiral downward into hells
Of our own making, our own doing,
Through this damnation we're pursuing?

As I look around, I try to cope,
Try to pray, to dream, to hope,
To hold on to the sweet illusion
That peace and love is no delusion
That we can change things if we try
On earth, in water, in blue sky;
And make this world the sacred place
We should cherish as the only race
That has the power to make it so
Before we lose more than we even know.

they were turned down when I submitted them to magazines.

I had as one of my professors the editor of our local newspaper, who gave me A's and once said that my news story about a town meeting was better than his reporter's story about the same meeting. He taught us how to do an application letter. Yet, when I twice wrote letters to him seeking a job with his newspaper, he didn't even answer my letters. Perhaps he was embarrassed to have to say no to my application.

I realize that consistent and relentless writing is needed to succeed at free lance writing. We just weren't equipped at that point to enable me to do that. Going to school gave me due dates to meet and prescribed assignments to do. I do much better in a structured situation like that. Now I had no deadlines hanging over me and no guidelines

to follow and no specific destination to target my work towards. I am sure all of us who were part of my "enable to write" crew were feeling the same way.

Another complication affecting my ability to earn a living is the body of rules that I live under because I am receiving SSI funds monthly and also receive support by having an Autism waiver. Don't get me wrong. This support is the reason that I can still live at home with my parents, which we all want to happen. The problem is that I can't accumulate more than a certain amount of money at one time without losing these services. I would have to earn only a little regularly over time or a lot at only one time to stay at home. So far --- no problem on this front! The only money that I have earned was the \$10 per column that I received from the college newspaper.

GETTING GOOD HEALTH CARE

Robert W. P. Cutler, Jr.
October 2008 AutCom Conference
Ann Arbor, Michigan

I am Robert Cutler. I live with autism every day. I want to talk about things that affect the health of people with autism like movement, allergies, anxiety, counseling, ordinary medical and dental care, etc., and what has worked for me. I have a team of doctors and therapists of whom I approve and they help me. I tell them what works and I depend on them to help me control my mind and body, and help my mind and body work together. They have helped me stay calm and in control. I no longer fear my body will freeze. I now move with ease. I am grateful for all the people who have helped me achieve my independence through the team method and who have helped my staff better understand me. I love them for keeping me safe and teaching me about my body

Movement, Exercise And Teresa: I once had fear that my body would freeze and I would not be able to move. I want to talk about how Teresa (sensory integration therapist) has helped me over the years to calm myself down when I get stressed. She helps make my body move smoothly.

Teresa and I have developed a sensory program. The futon helps my body reconnect when it goes apart and I can't control it. It feels good to have pressure on me. It helps me a lot so I

have approved of its use on me. It is a good thing. Yes. I now move with no fear. I know I will not freeze. I feel I have control of my body better than it used to be. I am happy to have Teresa in my life. She has helped my body to connect with my mind. I think that is why I can move better.

Exercise is good. I do the exercycle, arm cycle and I walk. It helps to keep me moving smoothly. We all can use the exercise. Walking soothes my mind. I like to get out and exercise to get healthy and I know I am getting older so I have to get in shape. I think that all children with autism should have access to sensory integration therapies. It would help them understand their bodies.

Allergies: I have allergies in the spring and fall and some in the winter. It makes my eyes itchy and my body hard to move. When my allergies are bad my eyes are burning sometimes. A wet cloth on the eyes can help. Medicine helps but I just need to take it easy and I don't need to be pushed to do much. When the allergies get better my body moves better.

Anxiety/Lorazepam: I get anxious sometimes. I try hard to stay in control of my mind and body. The medicine is good. The Lorazepam helps me to relax. The ocean wave tape and rituals also help to relieve my stress and the counter makes me feel good.

Sometimes repetitive movements are relaxing. I love to be able to go to camp. It is a place to

(Continued on Next Page)

(Getting Good Health Care continued)

relax. I can sit outside and hear the sounds of nature and the sounds of children's laughter. It soothes my mind and body to go there. It is a calming place. Rides in my van are also calming. Autism sometimes interferes with our emotions. Even when we become so overjoyed our bodies exhaust all our energies.

Seizures: A lot of people with autism have seizures. I know seizures are scary because I have had them. Having seizures scared me and it stopped me from having control of my body and mind. My brain got a charge that caused static in my mind. They came fast and lingered for a long time. They came at a time when my brain repeated itself and time was frozen like a picture. I couldn't move. Imagine your body freezing but your brain is fighting to move. It feels like an earth quake. The body shakes. Yes.

There were warning signs. Heat in my body. Visual aura did sometimes happen and some headaches related to tension and anxiety.

Cranial sacral therapy and medicines helped. I had to try different medicines. Laying down helped. But having autism seizures stopped me from growing to become what I should have been, a college dean or doctor.

PTSD: I have PTSD which causes flashbacks. I had headaches and felt weird and tense and sometimes didn't know why. It was scary when I lost control.

Thalia (counselor) has helped me bury those nightmares away so I hope never to have them again. She has shown me that I can move on. NIH should not ever support any program which uses aversive, painful treatment, period. There needs to be more money invested into people who suffer from PTSD because of being sent to institutions because they were different and society wanted not to help but hide us.

Medicine: I am doing good. My doctors work with me and respect me. My medicine is good. I tell them now to keep it the same. We have a good combination of medicines. I have been in control of my mind and body. No chemical straight jackets for me.

Medicines which work for one may be worse for others. Look at how the ramifications some have had to endure because doctors prescribed medicines without fully understanding the risks physically and mentally we had to suffer. We should not take mind altering drugs to control our

behavior.

People with autism have neurological problems for which no behavior treatment works. We need alternatives that work better than those which control and demean people with autism.

I think doctors should have training in understanding autism. Also knowing the doctor is a friend can help. We want healthcare where the doctors know the patient, notice our needs and if you see bruises investigate. We want to feel safe and to build a trust in you.

Dental: Everyone should have good dental services with proper cleaning and quality checkups. A dental visit is cheaper than hiring a behaviorist! If our teeth are neglected we will feel pain which many will call a behavioral incident. Disabled people may need extra dental visits.

It is time to fully fund dental, OT and counseling instead of control programs, yes. Shouldn't occupational therapy, dentists and counselors be given as much funding as programs using behavioral controls over a human being?

Until complete health, neuro and environmental studies are assessed, no child with autism should enter into a behavioral mod model. Yes.

I feel we should spend our money on getting the services we need. I feel there is no cure, just better understanding of us.

Conclusion: I want people to have a better understanding of autism. I feel NIH should invite many people with autism to Maryland. We could teach you the truth and mistruths about autism, yes. It would be the best way for you to gain valuable knowledge. We are humans; we are not a disease. I am all done. Yes.

Visit the AutCom Bookstore!

The AutCom Bookstore is operated by the Institute on Disability's Bookstore at the University of New Hampshire. It has a wide range of books on autism, all of which have been carefully reviewed.

You can reach the bookstore on the internet by two methods: 1. Go to www.iod.unh.edu. In the left column (under Menu) click on IOD & Autism National Committee (AutCom) bookstore; under "Shop by Category" click on AutCom Bookstore; or 2. Go to www.autcom.org. In the menu bar, click on bookstore. In the instructions for the bookstore, click on "IOD Bookstore." Under "Shop by Category," click on AutCom Bookstore.

Autism National Committee (AutCom) Policy and Principles regarding Facilitated Communication

POLICY: It is the policy of the Autism National Committee that everyone has something to say and a right to say it. Facilitated communication is one accepted and valid way in which individuals with autism can exercise their right to say what they have to say.

“It is hard enough to live in silence without anybody or anything making it harder or more uncomfortable.” - Sharisa Joy Kochmeister, Current AutCom President

PRINCIPLES:

- Everyone involved with people on the autism spectrum needs to be consistently open to and ready for opportunities to listen and to the obligation to explore any and all processes that enhance genuine communication and social connections between human beings.
- People with disabilities (including those on the autism spectrum) who do not communicate meaningfully through speech must have an available means of communication that allows their fullest participation in the world.
- All people have a right to communicate using their chosen method(s), and their communication must be respected by others. **To communicate is a right, not a privilege.**
- People who are denied access to whichever types of Augmentative and Alternative Communication (AAC) they require are denied their basic rights because communication is the basis of all other rights and the means by which those rights can be realized.
- Facilitated communication (FC) is one process to which those for whom this is already a viable form of AAC have an absolute right to access.
- Those who are not yet using Facilitated Communication and who are not speaking fluently have a right to be exposed to, and to receive, competent Facilitated Communication Training (FCT) in addition to being exposed to and receiving training in other specific processes and methods. These, as stated in the American Speech and Hearing Association (ASHA) Guidelines, must be part of a total communication approach that includes speech, signs or gestures, and/or access to low or high technology communication devices.
- The benefit of FCT in leading to FC as an acceptable and valid form of AAC has been established by (1) the number of individuals on the spectrum who are typing independently today; (2) the studies in which at least some messages were passed correctly; and (3) practical applications when individuals' messages about pain, discomfort, choices, and other personal information have been successfully addressed.
- The primary goal of FCT is always for individuals to achieve independent typing. However, given the complexity of challenges faced by individuals, total independence in typing and in demonstrating literacy may not be possible at all times and for every single person.
- Children whose oral language is either absent or delayed for any reason must have access to any and all forms of communication (including AAC and FC) that are necessary and appropriate to enable them to communicate meaningfully in chronologically age-appropriate ways.
- Literacy is essential for an FC user to maximize skills learned through FCT and to become an independent typist. Therefore, literacy must be taught to all students regardless of the apparent severity of their disability. This is particularly true for students with autism spectrum disorders, whose complex movement, anxiety, connectivity, and sensory differences may preclude their demonstrating their abilities in conventional ways.
- At all times, the “least dangerous assumptions” must be made regarding each person’s potential to learn. This is particularly true for people on the spectrum as well as those with other challenges involving communication. To be precise, cognitive potential should always be presumed to exist and a rigorous, systematic, and long- term commitment is required in order to unlock the doors of communication.
- FCT can help enable a person to overcome neuromotor, anxiety, communication, and sensory difficulties and to improve their pointing skills for other forms of communication, e.g., pictures and symbols, along with achieving literacy. However, literacy does not have to be demonstrated initially in order to attempt other methods of communication including, but not limited to, FC.
- Anyone attempting to introduce FC as a form of AAC must have at least the Beginner Competencies articulated in the Facilitated Communication Training Standards. Facilitators, as well as FC users, need

- to learn the range of technical skills essential to access and use FC reliably and validly with current and potential users. Those who provide training to facilitators, the facilitators themselves, and FC users require and must be provided on-going training, supervision, and support.
- Additionally, facilitators must adhere to strict standards in order to minimize facilitator influence (which AutCom acknowledges may occur) and to assure that all communication is generated and owned by the FC user. Intentionally guiding an FC user to a target is unacceptable under any and all circumstances.
- Funding must be available for FCT, facilitators, ongoing training, and the AAC device(s) each individual requires to communicate meaningfully.
- People with disabilities who use alternative forms of communication should be active and proactive at the local, state, national and global levels in shaping policies and practices of government agencies, professional organizations, and other entities that directly affect their lives. FC must be accepted in policy and practice as an equal choice among AAC opportunities. AutCom acknowledges that FC involves multiple forms of support provided by the facilitator, allows the FC user to communicate messages that differ in complexity and usefulness, and is highly individualized and based on the specific needs of the FC user. As such, using FC does not necessarily look the same from person to person. There is a wide diversity of supports and styles of pointing to targets involved and there is no single rote prescription of how to introduce or use FC. Instead, FCT and FC involve dynamic, active and long-term processes of identifying, implementing, and evaluating communication supports according to the Facilitated Communication Training Standards.
- AutCom reaffirms its groundbreaking 1992 statement in support of FC, and supports and endorses the TASH resolutions on communication and facilitated communication, the Breaking the Barriers project results, the work of the Facilitated Communication Institute at Syracuse University, and the information on FC reported in the Autism Society of America's journal in 2006 [c.f., "The Advocate", 3(1), 14-22].
- AutCom acknowledges that FC and many other forms of AAC may reveal competencies, feelings, and thoughts that were previously un-assumed and/or unexpressed. We also affirm that all individuals possess unique gifts and strengths whether or not they need some type of support to assist them in communicating those gifts and strengths.
- AutCom asserts unequivocally that there is nothing mystical, magical, miraculous or mythical about FCT or FC. Indeed, this is very difficult and challenging work for both facilitator and communicator.
- AutCom criticizes attempts to dismiss FC on the basis of studies that are poorly designed and/or whose results are incorrectly extrapolated to the entire population of FC users. In particular, we reject over-generalized claims that allege or imply that merely because FC is not valid for some people under some circumstances, FC is not valid for any person under any circumstances.
- AutCom additionally acknowledges that the existing body of research points to essential cautions in using AAC (including FC) with anyone who does not fluently and independently speak, sign, or write to communicate. Both genuine, userauthored communication as well as influence by others can occur in a given conversation involving any communicators, even those using oral language fluently.
- Facilitator influence is not an insurmountable obstacle to the responsible and dependable use of FC. Message-passing (in which the FC user communicates information that is not known to the facilitator) is a straightforward way of verifying FC's validity and can be assessed in everyday situations.
- AutCom always welcomes responsible research into AAC/FC using a variety of acceptable, valid, reliable research methodologies and standards. AutCom supports and endorses research that is currently underway as funded, for example, by the Nancy Lurie Marks Foundation. AutCom also notes that the American Psychological Association and other organizations have not precluded continued research into the use of FC.
- AutCom affirms that FC has already proven to be profoundly beneficial in the lives of many people by opening the door to reliable, trusted, and respected symbolic communication for the first time.

"As for FC, it is a tool I use to get where I wish to go. Just as a voice is used by those who speak." – Jenn Seybert

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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: _____

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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!

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

Anne Bakeman, AutCom Treasurer

3 Bedford Green

South Burlington, VT 05403

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