Volume 20, No. 1 - Winter 2011

THE COMMUNICATOR

A Publication of the Autism National Committee

Judy Endow

AutCom 2010 Annual Conference

AutCom's annual conference, held in Milwaukee, Wisconsin, October 15-16, was successful in many significant ways. Our partner organization, The Autism Society of Wisconsin and its administrator Jane Pribek, did an outstanding job of organizing the event. The convention hotel was hospitable and helpful, and we actually made a profit!

The conference theme, "Communication, Competence, Community: Nothing about Us without Us," attracted many thoughtful presentations. Our keynote presenter, Judy Endow, set things in motion by asking "Do autistic people have their own culture?" Her insightful and often amusing observations on this and other related questions got the conference started on the right foot.

In Friday's plenary session, Paula Kluth explored the gap between the dominant discourse in the professional field of autism and the stories of people on the spectrum themselves.

Saturday's keynote presentation featured Suzanne Oliver's presentation, "Moving Forward: The Impact of Rhythm on Functional Movement and Independence." Suzanne established the first Neurologic Music Therapy clinic in the country. Suzanne didn't just talk, she demonstrated her therapeutic approach with conference attendees and their support personnel. As we often say, seeing is believing! Her demonstration awakened interest in many at the conference.

As always, there were excellent breakout sessions in which people on the spectrum, their families and supporters shed light on the realities of life on the spectrum. Some of these presentations are included in this newsletter.

Newsletter readers who have not attended the annual AutCom conference should give serious consideration to coming next year when it will be in southern California in October (watch the website for more details). The AutCom conference is one of, if not the best, place to learn about, and understand better, living on the autism spectrum.

Editor's Note: The conference featured presentations on influencing public policy by Rob Cutler, Mike Hoover and Jacob Pratt. These articles will appear in the next issue of "The Communicator."

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In Memorium

Anne McDonald
01/11/1961 -- 10/22/2010

AutCom and all its members mourn the death of Anne McDonald. Anne was rescued, at the age of 18, from a horrible existence in an Australian institution. She was placed in the institution at an early age due to cerebral palsy. Rosemary Crossley, a teacher, experimented with physical supports that eventually allowed Anne to communicate. Because of this communication, the Australian Supreme Court allowed Anne to leave the institution and live with Rosemary and her partner. Rosemary soon began to try this support system with other non-speaking individuals with developmental disabilities, and FC was born.

The part Anne played in this world is best summed up in an address she delivered at Parliament House in 2008 when she won a National Disability Award for Personal Achievement. Here is her speech:

I spent my childhood and adolescence in a state institution for severely disabled children. I was starved and neglected. A hundred and sixty of my friends died there. I am a survivor.

That isn't a heroic achievement. Anyone who was put into a large institution in the times when large institutions were sugarcoated concentration camps was as much a hero as I was. They stayed alive when they could and they died when they couldn't. Such heroism is easy to achieve in giant barracks where the prisoners stay alive through being cheery enough to attract a staff member to give them that vital extra spoonful of food.

I wasn't exceptional in anything other than my good luck. I was selected for an experiment. Rosemary Crossley wanted a subject for her Bachelor of Education literacy project. She chose me. The aim of the experiment was to see if I could make gains in my tight-armed pointing to blocks with different colors on them. Rosemary found I could point to colors, then to words, and then to letters. She taught me to spell and to make my wishes known.

I made known my wish to leave the institution, and then all hell broke loose. I went to the Supreme Court and won the right to manage my own affairs. Unfortunately, that didn't mean that the institution offered the <u>other</u> residents the right to manage <u>their</u> own affairs. I was an exception. Through no desire of my own, I was out front in the struggle to get rights for people without speech.

I tried to show the world that when people without speech were given the opportunity to participate in education we could succeed. I went to Deakin University and got myself a degree. That, too, was seen as an exception.

I gave papers and wrote articles on the right to communicate. I set up a website to show that there was hope for people without speech. People thanked me for being an inspiration; however, they didn't understand why there weren't more like me. They continued to act as if speech was the same thing as intelligence, and to pretend that you can tell a person's capacity by whether or not they can speak. <u>Please listen to me now</u>.

The worst thing about being an inspiration is that you have to be perfect. I am a normal person with only normal courage. Some people who should know better have tried to give me a halo. Anybody could have done what I have done if they too had been taken out of hell as I was.

If you let other people without speech be helped, as I was helped, they will say more than I can say.

They will tell you that the humanity we share is not dependent on speech.

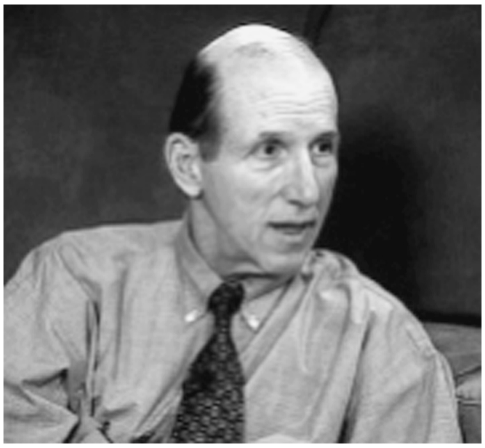
They will tell you that the power of literacy lies within us all.

They will tell you that I am not an exception, only a bad example.

Many are left behind. We still neglect people without speech. We still leave them without a means of communication. It should be impossible to miss out on literacy training, but thousands of Australians still do.

As Stephen Jay Gould wrote, "We pass through this world but once. Few tragedies can be more extensive than the stunting of a life, few injustices deeper than the denial of an opportunity to strive or even to hope, by a limit imposed from without, but falsely identified as lying within."

In Memorium



Stanley Greenspan 6/1/41 - 8/27/2010

In Tribute to Dr. Stanley Greenspan

by Barry M. Prizant

Over the past 20 years, I had the great privilege to get to know Stanley, shmooze, work and write with him, and share a podium with him at a number of his annual conferences. Having been exposed to much of his incredible work in the area of at-risk infants and multiple-risk families in the '80s, before he brought it to the arena of autism, I was quite in awe of meeting him in the early 90's.

His persistent intellectual curiosity and fatherly support not only challenged me, but pushed me and countless others to always do better, think more deeply, and be more reflective in our efforts to support children and families. I'll never forget his constant urging - Barry, put more AFFECT in your work - meaning that we always need to look through the window of relationship when considering child and human development, whether addressing issues of language and communication, social development or cognitive development, and whether we are talking about typically developing children or children with special needs. He always pushed us to understand all people as having strengths as well as challenges, and different learning styles. By doing so, he leveled the playing field and engendered greater respect for all by blurring the artificial lines between "normal" and "disabled".

And indeed, as I look back to where I was and where I am now, I will always be grateful for Stanley's advice and friendship. He is the one person who moved us to always look at all children, especially children with autism, as capable of developing deep relationships, regardless of what the literature and other "experts" had told us. He challenged and refuted mechanistic traditional behavioral treatment approaches as disrespectful and superficial. In doing so, he has forever changed the landscape of treatment and education for so many children and older individuals with special needs and their families. Bless you Stanley, you have changed the world for the better and we will miss you terribly.

Grieving for David

by Barbara Cutler

Renee Whaley was chubby and jolly, a feisty and relentless advocate for children with autism, indeed for all children with disabilities. She was also an incorporator for AutCom and served on AutCom's first Board. She never hesitated to remind the rest of us that "Advocacy is not for Sissies," and that we were in it for the long haul.

Renee had one child, David, and he had autism. She adored David; he was the love and light of her life. She spoke of him often with great devotion and sometimes with humor as she and her son dealt with a system that had little understanding of autism.

When David entered his teens, he had fairly uncomplicated surgery. While in the hospital he caught pneumonia, and in a few days he was dead. The unthinkable had happened. David was suddenly gone.

Renee, being Renee, continued her advocacy for other children and their families after David's death. I heard no more for a few years. At a national celebration of IDEA in Washington, Renee, the ever constant advocate, was present. She had lost a substantial amount of weight but did not have the look of the happy dieter who had become several sizes smaller. She looked pale, gaunt, listless and utterly sad as we spoke of David. After a few minutes she moved on to circulate, still the advocate at work.

I never saw Renee again. Several years passed, and I learned that Renee had died. She was barely in her fifties, if that. I could not learn of the cause of her death. Remembering how she looked in Washington, it was as if she had just faded away, as if life was too sad, too painful without her beloved David.

I think of Renee's devotion and feel anger toward those groups who present the worst possible images of children with autism, and how they tend to excuse infanticide or make it somehow acceptable. Remembering Renee's devotion and commitment, I know she would agree with me.

The Role of Communication in Thought

by DMan Johnson

Anna Stubblefield & DMan Johnson

Last year I gave a paper at the Society for Disability Studies conference. A woman in the audience asked if I was able to think before I had access to communication. I understand that this looks like a logical question, but it is pretty silly.

People have thought that thinking requires language. I agree, but they are wrong that language needs communication. They are working under the assumption that the only way to learn language is through interaction. For example, Jean Piaget, an important psychologist from the mid-twentieth century, believes that children learn language (logic too) by talking. He argues that they learn through having grown-ups talk with them (Piaget 1981, ch. 8).

On the other hand, Steven Pinker, a neurologist from Harvard, looks at things differently. His theory is that thinking in language is built into the human brain. He justifies his belief with the following evidence.

Pinker argues that children learn at least some abstract concepts before they limp into speech. For example, infants looking at Mickey Mouse dolls look longer if the number is not what they expect:

> “The developmental psychologist Karen Wynn has recently shown that five-month-old babies can do a simple form of mental arithmetic…In Wynn’s experiment, the babies were shown a rubber Mickey Mouse doll on a stage until their little eyes wandered. Then a screen came up, and a prancing hand visibly reached out from behind a curtain and placed a second Mickey Mouse behind the screen. When the screen was removed, if there were two Mickey Mouses visible (something the babies had never actually seen), the babies looked for only a few moments. But if there was only one doll, the babies were captivated—even though this was exactly the scene that had bored them before the screen was put into place. Wynn also tested a second group of babies, and this time, after the screen came up to obscure a pair of dolls, a hand visibly reached behind the screen and removed one of them. If the screen fell to reveal a single Mickey, the babies looked briefly. If it revealed the old scene with two, the babies had more trouble tearing themselves away. The babies must have been keeping track of how many dolls were behind the screen, updating their counts as dolls were added or subtracted. If the number inexplicably departed from what they expected, they scrutinized the scene, as if searching for some explanation. (Pinker 1994, 59).”

Thinking does not need communication. In Pinker’s book, he motions to the idea that people learn grammar before they start speaking. I might not be able to talk, but I think grammatically perfectly. The mostly believable idea that grammar is learned through talking is not true.

Pinker’s second clue is how people think in different languages. He shows that not only do we learn grammar in the absence of talking, but it is possible to learn multiple grammars this way. Linguistical knowledge is not predicated on knowing how to talk in the language.

In thinking about how people learn to read in the absence of communication, it is useful to look at studies on how gifted children learn to read. In an article called “Children Teach Themselves to Read,” the people interviewed could read young by teaching themselves (Gray, 2010). Thinking about how they do that helps us to understand how you can legitimately get literacy with no communication.

People think that young people learn by being taught. But they can teach themselves. Looking at books is only one ploy. Other ways include playing with alphabet blocks, hearing their parents helping their brothers and sisters, looking at labels and signs, and also, television.

There are lots of studies permitting us to know how gifted children learn (Cunningham, 2006; Aldridge and Rust, 1987; Price, 1976). But listening to FC users is apparently not valid. Hopefully, people who are interested in literacy will start to notice that we know how we learned.

Judging from Pinker, not making too many guesses from only the experiences of typical children but looking how children like me learned to use language, then one can see that people learn language in the absence of communication.

However, I must not limit the usefulness of communication. I propose that only people who cannot talk learn language mostly by thinking in place of by communication. People who talk mostly learn language by talking. I think that the ability to talk makes people learn thinking differently. If one could not talk, then the ability to learn lots of things in the absence of communication kicks in.

I might begin by pointing out that people like me jump (that's my term for feeling autistic) when people look numerous. When there are people around, I look like I might be copying them, but I might be learning. I now know how to read because I looked at things people were reading.

People might not look like they pay attention but they learn things. You might just not know they are learning. People like me jump lots, but my learning has been going on.

I believe my knowledge of language lies in listening to people talk. I learned to use language in my head before I began communicating. But having communication helps me think more clearly. I might not be making sense in my head. Communication means I get feedback.

I got my means of communication later than most people. But people know how to think in their heads before they learn to talk. Therefore, learning to communicate is not necessary for learning language.

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Healthy Living

by Mike Pribek

My name is Mike Pribek and I am from Two Rivers, Wisconsin. I will be 20 years old in 3 weeks,and I graduated from Two Rivers High School in 2009. I am currently in the process of doing a job assessment and job search with Dept. of Vocational Rehabilitation, but I have been volunteering at the Two Rivers and Manitowoc Public Libraries for about 2 years now. I have also taken online computer courses through Lakeshore Technical College. My favorite things are NASCAR–I've been to several races, video games–I have quite an extensive collection, and anything to do with math. My mom says that I have a calculator in my head, so there is no need to have one in our house as long as I am there. I am able to calculate things in my head that most people need a calculator to do.

Up until 3 years ago, I had been on a very limited diet. I was very particular with the foods I ate. I ate only dry cereal, McDonald's French fries, crackers and potato chips. It was very difficult when we went on vacations. I loved Pringles Sour Cream and Onion potato chips, so that is what everyone gave me for my birthdays. My parents tried to get me to try other foods, but the texture of certain foods made me throw up. I eventually added other crunchy foods, such as Ore-Ida onion rings and fish sticks, made in the oven with lots of salt.

When I went to see Dr. Greene for my annual checkup on April 13, 2007, I weighed 168 pounds. Dr. Greene told me that if I wanted to remain healthy, I needed to start eating healthier foods, adding fruits, vegetables, chicken, turkey and fish to my diet, and start exercising. He recommended that I do 30 minutes of cardio exercising, such as walking, running, or biking; and 30 minutes of weight

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strengthening exercises 3 times a week.

When we left the doctor's office that day, I told my mom that I wanted to stop at Pick 'N Save to buy fruits and vegetables. That day we bought carrots and grapes. I liked them! Since then, I have added many other healthy foods, both fruits and vegetables, along with chicken, turkey and fish. I eat Natural Ovens breads, bagels, buns and cookies. Natural Ovens is a bakery in Manitowoc that makes baked goods from all natural ingredients, using whole grains in their products.

My parents are always asking me to try new foods and I get frustrated with them, because I am afraid I won't like them, and it is scary for me to try new foods. But many new foods that I try, I find that I like, and am then happy that I tried them. I also have added hamburgers, hot dogs, brats, and pizza, which are fun foods, which Dr. Greene says is okay.

On April 15, 2007, I started walking on our treadmill 30 minutes, 3 days a week. I started losing weight. On December 19, 2007, I joined Anytime Fitness and started an exercise program consisting of cardio and weight strengthening exercises.

Within a year, I had lost 40 pounds. It has been 3 years since I started living a healthier lifestyle, and I am still eating healthy and exercising. On August 4, 2008, our local newspaper, the Herald Times Reporter, did an article on me and the lifestyle change I had made. Anytime Fitness in Two Rivers still has the article hanging in their center.

Besides eating healthy and exercising, I am still learning how to keep my sensory system regulated through different types of sensory integration. I find that rubbing and massaging my hands, arms and feet are very relaxing to me and help me to re-regulate myself. I bought a very nice foot massager almost 4 years ago that I use quite regularly when sitting in my favorite rocking chair. I also rub my hands and arms when I feel myself getting over-stimulated. People used to do this for me, but I learned to do it for myself in middle school. A few months ago, I had my first massage and found that very relaxing so have now integrated that into my monthly schedule.

Another type of therapy I have found for myself is our dog Snickers. Mom brought Snickers home in March of 2009, just last year. She will be 2 years old in January. When she first came home, I didn't care for her. But within about 4 months of Snickers living in our house, I grew to like her and found that she provided me with sensory integration and relaxation that I never expected. Snickers likes to jump up on me when I am sitting in my chair, and she licks me all over. She likes to lick inside my ears, and she especially likes to lick my face, neck, arms and legs, right after I am done exercising. I lay on the floor and she goes to work, and I find it very, very relaxing. She is a fun dog and loves being by me.

Aaron to AutCom

Aaron Greenwood lives in Alberta, Canada, and attended our conference in Edmonton in 2007. He is now 13 and in the 7th grade. Aaron was not able to attend our 2010 conference but sent this message:

I am so happy to have this opportunity to share my thoughts on autism. Only on my diagnosis did my life truly sail on to disaster. I was a happy child. Now I remember much of my childhood on my family farm. It was a life just like many kids. Lots of love and kindness was shown to me.

In freedom I was home. I gave my family a lot of credit for accepting me as I was, not wanting another child. Usually my life was happy. Upon my diagnosis my life changed as lots of people tried to change who I was. I did not want to be changed. Most great, just people really realize every autistic person dearly wants only to be free. Realizing who they are is a gift from God. The truth is realizing that your child is truly special. Not created as broken but created as loving, capable, truly gifted people. God dares to create all of us, perfectly free to be his children. Until we realize he does not create garbage, but only gifts of his love, will we ever understand autism. Free only to dare to be different is ok.

I was never ok with being treated like I needed to change. It is a horrible reality only to have people in power treat you like an object without asking you or respecting you. In my life my parents always treated me with respect, only in my life outside my home was it different. I have had many people speak for me in my life. I needed only to be listened to. Just need people to, in love, respect in love. In love only kindness should be your true, just kings of your life. I am so happy to be treated as an intelligent person with much to say in the world. I must emphasize to all parents and caregivers to remember the person inside the body of autism, only love will be treated as ok. Of just anyone who feels they must treat us with disrespect, then leave us alone. Kindness is shown in respect, dear loving family members and friends. Love us as we are, not as who you want us to be. Kindness is God's way.

FC has been a wonderful freeing gift. A great tool for me to realize my thoughts and beliefs. I am so most happy to have this form of communication available to me in my world. It has opened up my great voice. In my world, without FC, it was dark and freedom less. I was so lost and alone in my ever sad world. I am so thankful to have Char [Char Brandl] teach me and my family the importance of FC in the lives of autistic people. In many ways it is so much responsible for where I am today. I also thank Gail [Gail Gillingham] for being the first person to show really how wonderful I am in this world. These two people mean so much to me and my family.

I truly think that in this world there is too much hate and truly angry people. Only in love can we heal this world. Love is the only way. Autism is not a curse, not a life ender, not a life killer. I hope to let all of you know that my life has a purpose, a plan, a life's longing to be a part of this world. Kindly remember that reality for some is not a reality for others. Only that we must respect everyone's place in this world. Only then will we lovingly, fantastically, joyfully, freely be allowed to live together. Thank you for listening to me. Kind of you to take the time to hear my ideas.

Community, Competence and Communication

by Daniel McConnell

I wish I could give my presentation on love. See how love moves through the day when it is given free reign to be inside of us? It is always moving around and in and out. It takes us by surprise when it moves our way! Even if we don't acknowledge its presence in our lives it is the world's gift to us.

I think friendship is a hard thing to determine for someone like me who needs so much help in life. Can I keep friends always? They come and go in my life but the feelings don't go away even if the friends do.

The community I'm thinking of is all the others who do not talk. We are all friends in spirit because we know what it is like to be silent citizens. We are the people who make the most of our lives by watching and listening and never really participating in the conversations going on around us all the time. It is a very strange thing to know the answers or have an opinion that never gets spoken.

I need the help of others but sometimes they are not so helpful. They can't imagine my response so I can't have the chance to say it. They don't think to ask all the time. The people who don't talk are the ones who know what it is like. They all have the same dream as me—to be able to tell our thoughts easily like everyone else.

But it is more than just typing our thoughts to others. It is having thoughts that are reluctant to be out in the all-judging world of humans. The reluctant thoughts have their own sense of timing, and when they are not ready to come out, nothing in the world can make them. They are reluctant because they fear so much in the world. The fearfulness is at the base of the problem. Fear is running the show. I can't think of another way to say this, but fear of your responses is the biggest roadblock to our communication, so those of us with fearful hearts have a community of our own.

My community of friends is never going to include the people who are unkind towards us…who are willing to be masters of the universe instead of people amongst people. When they come into a room my thoughts hide themselves away. I never could get a whole thought out in the presence of the masters. The others who do not talk are much the same, but some are stronger than me and they can get their thoughts out in any situation. It is from experience mostly. I am always ambivalent about telling my thoughts because they are the only thing I truly own. All of us must be alert to being judged harshly and not give up when that happens.

I can rarely do what I want, exactly. This is the great heartache of my life. Normal people make it seem easy to do things but it is not easy at all. I would be totally different if I could do what I wanted to do.

Competence comes with a hook that can undermine the rest of life. Those of us who are less competent can be more free from the pressures and responsibilities of normal life. That can be both

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good and bad. To me, being competent means being able to do what I want instead of being under the influence of my obsession. Competence goes down the drain with emotions running out of the tap. But if not for emotions, my competence would never rise to the occasion.

If I could be more competent I would stop being angry at life. I can't help myself or my behaviors try as I might. But it is not what the [larger] community wants to see. Behavior really gets in the way. The crux of my community wish is to just be accepted as I am. Tell me how to do that and I will be a happy autistic guy.

I am ready to now talk more about the third C word: Communication. Communication is the ultimate salve for emotions.

Typing makes me feel like I have the other two words: competence and community. My competence comes through typing as does my community. That is my greatest hope and joy in my life. We all know each other even when we first meet because we have the same experiences of not talking. It is an amazing thing to be in room with other typers. It is a community like no other. I love that community more than anything except, of course, Mom.

I think we are all called to a very special mission.

I get emotional when I think of the others who still don't type. They are still trapped like I was, and they don't know how much better life is when you can type. I want to be able to give them what I got. Communication is the ultimate salve for emotions.

Everyone should consider what communication really means in terms of community and competence. It is the key to both. Competence cannot be seen without communication. And community depends on it too, but not in the same way. Community can happen with or without communication. It is just a different type of community because of words. You can know your community in a different way.

I remember my life before typing when all the great thoughts just dissolved into a sea of nothingness of my locked-up mind. It was pure torture everyday. The thoughts would come in and then have no place to go. They would circle around but never land anywhere. It is hard to describe just how hard it is to have thoughts that don't land.

Try having just one thought die on the vine and you will know what it is like to be without words. That, if nothing else, makes us a community.

Slow Clothes

Attendees were invited to try on and rearrange the many interesting pieces of fabric.

The 2010 AutCom Conference featured a "Slow Clothes" display by Erin Manning. Erin Manning holds a University Research Chair in Relational Art and Philosophy in the Faculty of Fine Arts at Concordia University (Montreal, Canada). She is also the director of the Sense Lab (www.senselab.ca), a laboratory that explores the intersections between art practice and philosophy through the matrix of the sensing body in movement. In her art practice she works between painting, fabric and sculpture (www.erinmovement.com). Her current art project, entitled *Folds to Infinity*, is an experimental fabric collection composed of cuts that connect in an infinity of ways, folding in to create clothing and out to create environmental architectures.

Hoover "Uncommon Student" Award Speech

by D.J. Savarese

D.J. Savarese

AutCom Member DJ Savarese won a Herbert Hoover Uncommon Student Award. Here is his entry, which was also his 2010 conference presentation.

Dear Mr. Hoover,

I want to thank you for treating me and my people with respect. I feel honored to be here today. I look dear, but fear is high. If you ignore my strange behaviors and hear my heartfelt thoughts, deserting fear and freeing hope, I feel confident that you will be proud of what you inspired me to do.

You often talked about a topic near and dear to my heart: freedom. In this quote you identify so many of the things most non-speaking people are denied: the freedom to pattern their own lives, to develop their talents, to earn, to acquire property and security, and to create a family. Like you, I was orphaned at a young age, but as I deserted fear and learned to read and write, I greatly felt empowered. I was able to break the barriers and be included as a real student, and like you, I have never forgotten the pain, sadness and imprisonment that I felt and saw others feel. For that reason I now dearly advocate for others who cannot speak, and I imagine I will continue to do so as long as I live.

The question is how best to do this. From an early age I freed my people by writing and presenting at conferences. I published my work in books, newspapers, and online journals like Disability Studies Quarterly. I even appeared on Anderson Cooper 360 in an Interview with Dr. Sanjay Gupta, in which I proposed a national summit to allow non-speaking people to represent themselves. Still, it wasn't enough. Then I got the email from my counselor encouraging me to apply to the Herbert Hoover Uncommon Student project.

You once said that "Words without actions are the assassins of ideals," and I took that to heart. I decided to use this as a chance not just to reach those wealthy enough to attend expensive conferences and buy hard-backed books, but to also encourage every possible non-speaking person I could, by creating permanent, continually evolving resources that would be free and available to anyone in the world. I'd like to tell you a bit about all three of them: my on-line gallery, my free trainings, and my website.

You wrote hopefully that in the great mass of our people there are plenty of individuals of intelligence from among whom leadership can be recruited. I wanted to show everyone that the same is true for non-speaking people. Many of us work great feats but as individual voices. Among us are many published writers, three film stars and one screenwriter who actually made it to the red carpet. By gathering our work in one place, I hope to show people the breadth of kindness, talent and experience we have. By showing kids that fresh thinking real Autists exist, I hope to encourage them to freely learn to read and write.

The gallery is called "Finding Our Voices" and contains treated respectfully people's work from England, Sri Lanka, and the United States. I encouraged both established self-advocates and also beginning typers to submit pieces.

Some of the pieces are practical and straightforward like the words from my friend Chammy. Others are crafted poems. And still others, like the one written by Larry Bissonnette, captures the language, midway between poetry and prose, that many of us use. Each person longs to be understood.

Like you, I also believe that education can free those who are voiceless both literally and metaphorically. However, it can also hopelessly

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segregate and oppress kids by assessing them as retarded. I know this from my own experience. In the second part of my project, I did two trainings, one of which was also available online and can still be accessed for free from the website of the Center for Autism and Related Disabilities in Gainesville, Florida, the organization that sponsored the training. This day long training, entitled "Easy- breathing Autism: Supporting Relationships, Literacy, and Self Esteem," was designed for parents and educators, and was attended by people as far away as Virginia, Iowa, Texas, and Vermont. I was especially proud that the newly appointed autism specialist for the Florida Department of Education tuned in online and later thanked us for an interesting and informative presentation. The training was a mixture of information about how non-speaking Autists represent themselves, what makes inclusion work, and how to use modifications to teach reading and writing to non-speaking people in regular education classes. As can be seen from the comments people wrote, having a person who types to communicate, run and create trainings is what each free wants. In the future, I hope to develop enough stamina to do an entire day's training on my own.

The second training, called "Poetry: Raising Understanding, Yearning to be Understood," was a practice session I created for people who are still practicing typing or learning to read and write and deserts the idea that all we desire is to communicate basic needs. It was for the people in Iowa and Illinois who type to communicate and their support providers. So many people are deaf to our dear selves. We need opportunities to meaningfully tell people who we are and what our dreams and feelings are.

The third part of my project involved creating a website for educators and parents that assumes competence and shows them how to use the regular assignments in school to freshly create new paths to literacy. It involved a lot of work, choosing the design, reading through all of my work from elementary school, and inputting the information. I'm guessing your favorite part was the minischedule and modifications I used when I visited here with my class in the fourth grade!

As I mentioned earlier, my project is a lifelong mission. The Americans with Disabilities Act was passed nearly 20 years ago. In it kids are supposedly guaranteed an education in the least restrictive environment. Sadly, most non-speaking kids in Iowa and the nation are still taught in separate classrooms or at home. So my people and I will work on. I intend to continue adding to and updating the gallery, the trainings and especially the website. As recently as last night, I accepted new submissions and my school intends to perform a new Readers' Theatre I have written using many of the pieces from the gallery. In 2009, I wrote and assistant–directed my peers in our school's Varsity Readers' Theatre. The piece, which recounted my personal journey from foster care to self-advocate and beloved son, received Outstanding Performance at the State Level. I intend to submit this one to Thespian Playworks, in the hopes it might be performed at the annual Thespian Festival in Lincoln, Nebraska, this summer.

I plan to create and lead another meaningful practice session for the Iowa group of emerging typists. I also hope to continue learning more about the disability rights movement and to educate more people as I head to college next year.

In closing, I'd like to leave you with one final quote. Like you, I am fortunate. As you said, "My country owes me nothing. It gave me. . . a chance. It gave me schooling, independence of action, opportunity for service and honor. In no other land could a boy from a country village, without inheritance or influential friends, look forward with unbounded hope.

Thank you for this opportunity to give others that chance.

Sincerely, DJ Savarese

Readers of "The Communicator" should read this important essay:

Identifying, Educating, and Empowering Allies

by **Phil Schwarz**

It can be found online at

http://www.autistics.org/library/allies.html

MARCH 10th & 11th:

16th Annual Prizant/Domingue ASD Symposium
in Cranston, RI.

For further info: **Call 508.965.5705**

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: ____________________

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I want to: _____ Renew my membership _____ Become a member

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In the envelope provided, I am enclosing my membership fee of: _____ $10.00 (person with autism)

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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

Autism National Committee
Barbara Cutler
7 Teresa Circle
Arlington, MA 02474
www.autcom.org

January is the Time to Renew or Join!

Membership form on page 11

Celebrating 20 Years!

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 Doug McClennen, 619 N. Sheldon Rd., Plymouth, MI 48170 - or email him at: dmc@umich.edu. 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.

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