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AutCom 2012 Conference – The Best Kept Secret

Posted on October 8, 2012 by Ariane Zurcher (reprinted with permission)

<http://emmashopebook.com/2012/10/08/autcom-2012-conference-the-best-kept-secret/>

The Autcom conference was a fleeting glimpse into paradise. A tiny taste of how the world could be were we accepting of each other, treated all people as equals and with respect, without prejudice, without assumptions, without bias. Autcom was a window into how the world could be, but isn't. Not yet. Words do not do this conference justice. How could they? How do you describe a room full of people who are connected not through race, nationality, religion, political views or neurology, but instead are connected by an idea. A vision. How do you describe that?

Accommodation - it's a word we hear, but what does it really mean? At the Autcom conference it meant waving hands at the end of a presentation instead of clapping, lowered lights, snacks that included gluten-free and casein free items and non dairy alternatives. Accommodation meant no one stared disapprovingly at anyone who stilled or made noise or got up to leave in the middle of a talk. Accommodation meant people were polite and moved chairs that might be blocking someone's ability to come or go. It meant using a microphone or repeating a question for those who weren't able to hear the first time. It meant being respectful and considerate when someone came up to peer at your name tag and it meant understanding that when that person gently touched your hand after a presentation it was their way of thanking you and I defy anyone to



Ariane Zurcher (L) and Amy Sequenzia (R)

not see the beauty and love in that. Accommodation meant slowing down while someone typed their answer or question or thought. It turns out accommodation means being a thoughtful, considerate human being

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Save the date!
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Lighting The Way
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(See form on page 11 and use attached envelope)

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Web Site: www.autcom.org

(2012 Conference continued)

who is respectful of others. How is it this isn't done automatically, as a matter of course. How is it that we as a society have drifted so far from this very basic and easy way of being in the world?

The single biggest issue I had with this wonderful conference was that there were too many terrific things going on at once and it was impossible to see and hear everyone and everything. To give you an example of this - on the first day of the conference after Ari Ne'eman's welcome and an opening keynote address by Jennifer Paige Seybert, was Savannah Nicole Logsdon-Breakstone's presentation - Loud Hands Project's Neurodiversity 101. At the same time, Larry Bissonnette, Pascal Cheng, Harvey Lavoy and Tracy Thresher were doing a presentation on Supported Typing, which I really needed to go to in order to access whether this might be something we could use to help Em communicate more effectively, but next door to them was Nick Pentzell, Hope Block, Jacob Pratt and Autumn Dae Miller presenting "Rated "R": That Oh-So-Difficult Topic". I cannot tell you how much I wanted to hear them too

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(L to R) Larry Bissonnette, Harvey Lavoy & Tracy Thresher

and later heard from others that it was a not to be missed presentation, sadly though, I missed it. Human Development Journey was presented by Cecilia Breinbauer about using DIR, which was the method Richard and I were trained in by the late Stanley Greenspan, after abandoning ABA.

That evening after dinner and a wonderful performance by Jordon Ackerson who reminded me of Emma because of his beautiful voice, we watched "Wretches and Jabberers," with a Q&A with Larry and Tracy. This was my third time watching this documentary, which I posted about last month. I asked them about self-injurious behaviors, something both engage in during the film. I asked for their opinion about the commonly held belief by many that SIBs should be thwarted and how parents and caregivers are often unsure how to deal with this. Tracy typed, "That was years of frustration with no way to reliably express myself working its way out through my behavior the problem was lack of communication which pissed me off." Larry typed, "I lived in an institution so I was locked in arms of restraint its legal but immoral and only represses anger nothing looks more kind than softly spoken words and lit up smiles."

Read that again. "... nothing looks more kind than softly spoken words and lit up smiles." The presentations were terrific, but it was what is possible that this conference represented, which affected me most profoundly. The AutCom conference was an example, all organizations who say they are interested in Autism and helping those who are Autistic, should follow. Autistic people make up a large portion of their board, Autistic people led more than 50% of the presentations, the audience was at least half Autistic, if not more. At my presentation there were more Autistic people than not, for which I was truly honored by. The conference showed what the world could be like if



(L to R) Scott Robertson, Autumn Dae Miller, Nick Pentzell, Gwen Waltz

we work together, reach out to each other, include everyone despite our perceived differences with love, compassion and kindness. Accommodation is less about accommodating and more about getting in

touch with our humanity and what it means to be alive and sharing this planet together. Accommodation and inclusion means we ALL benefit.



Mary Schuh, Bookstore Coordinator



Lisa Lieberman accompanying her son
Jordon Ackerson

Meeting the Challenge: A Guide to Respectful, Effective Planning, Advocacy and Support with People who Have Puzzling Behaviour

by Susannah Joyce – reviewed by Sandra McClennen

Order online from: <http://www.realizationstraining.com/Resources-from-Realizations.html>

Susannah Joyce learned from Herb Lovett, and her book reflects this. Written for families, friends and paid supports, it explores behavior through the varied aspects of our shared human needs and experience. It emphasizes understanding rather than controlling.

Joyce reminds us that we need to presume competence and that what we call "behavioural challenges" has a rational or biological reason. Anecdotes, often from her own experience, promote understanding of her approach.

She calls for a team approach. She encourages developing circles of support for people. She reminds us of how easy it is to be unintentionally cruel by not constantly comparing our actions to our values.

She addresses the language that we use - not just "person first" language, but the terms that drive me crazy - compliance, manipulation, mental age, high-functioning/low-functioning, and readiness - to name a few. There are more, and Joyce has included all that are on my list and a few that I have added to my list.

Those who read this review almost certainly believe in these values. Joyce's checklists, questions, reminders give us tools to keep ourselves on track and to teach others. For example, she suggests using a biographical timeline to develop

compassion for those whose lives have been chaotic, unloved and controlled by others. Reading some of the examples certainly sheds light on those people's puzzling behaviors.

Joyce talks about the importance of communication and quotes, among others, Jenn Seybert, who has been a member of AutCom's Board of Directors.

She quotes Dr. Ruth Ryan extensively, addressing identification of physical problems, pain, nutrition, and medication. People with a developmental disability can also have a mental health problem that needs to be identified and addressed. Joyce gives many examples of the value of counseling and therapy, both individual and group.

There is a chapter on trauma that is very inclusive of the types of trauma that might have been experienced by a person with "puzzling behavior." There is a section on the experience of grief and grieving.

For every issue she brings up, Joyce makes helpful suggestions. I recommend this book for everyone who has a family member or a friend with a developmental disability and puzzling behavior and for all whose professions bring them into this group of people. Not only is it a good reminder for all of us, but it is an excellent book to share with others to help them understand our point of view.

More Pressure to Close JRC

by Lydia Brown, Georgetown University Student

In December 2012, the Centers for Medicare & Medicaid Services (CMS) sent a letter to the Massachusetts Executive Office of Health and Human Services announcing a prohibition on the use of Home and Community Based Services (HCBS) waiver funds for individuals in facilities that use electric shock aversive interventions, even if the individual is not receiving those "treatments."

In the same month, the U.S. Food and Drug Administration (FDA) sent the Judge Rotenberg Center (JRC) a warning letter regarding use of unapproved devices--the Graduated Electronic Decelerator (GED-4)--and ordered the JRC to attend a meeting in early January at the White Oak campus in Maryland regarding compliance. On January 9, Occupy the JRC organized a protest of the GED devices at the FDA's Maryland site during the JRC's meeting.

On February 14, Massachusetts Governor Deval Patrick instructed the Attorney General to file a motion with the Bristol County Probate and Family Court to vacate the 1987 consent decree attached to

the 1986 settlement in the then-Behavior Research Institute's lawsuit against the Director of the MA Office for Children. The 1987 consent decree has been the JRC's primary legal weapon for justification of their use of painful aversive interventions.

On February 22, New York City Councilman Vincent Gentile, who introduced legislation to require oversight for developmentally disabled students in out-of-state placement and the 2009 law requiring monitoring of out-of-state residential facilities, issued a letter calling for the withdrawal of all NYC children from the JRC.

On March 5, UN Special Rapporteur on Torture Juan Méndez, presented a report to the UN Human Rights Council in Geneva that named the continuing existence of the JRC as a violation of the UN Convention Against Torture. Both he and his predecessor, Manfred Nowak, have condemned the JRC's practices. In the United States, the U.S. Department of Justice's Civil Rights Division is continuing its investigation of the JRC for civil rights violations.

Beyond Autism

Presentation by Rob Cutler and Michael Dowling at AutCom 2012 Conference

Michael Dowling, Executive and Artistic Director of the Medicine Wheel Studio in South Boston, began his work in 1997 with 17 young men and women who were survivors of drugs, alcohol and violence. They wanted a voice. They began by building a memorial to lost friends on an historical site overlooking Boston Harbor. So began a program of supports, advocacy and recovery through artistic education and exhibition.

Two years later Michael invited Rob Cutler to meet the troubled youth served at Medicine Wheel to see if they would "click." Click they did, with Rob communicating his support, understanding and wisdom using his access to communication, FC.

At the local St. Patrick's Day parade Rob was also to show his courage in how to take a risk. As gay and lesbian marchers, jeered by some onlookers, passed by, Rob moved past the police to hand out roses. It was not his fight and yet it was. Michael cited Rob as his teacher and leader as he learned from Rob how to take a risk.

In the 12 years Rob has mentored 16 boys in recovery twice a week, changing every six weeks, he has served about 1000 young people who may or may

not understand his autism but know him as a man of compassion and wisdom. In the quest to support a just and inclusive society, Rob joined me and many of our young people and others in creating an event to honor Martin Luther King, Jr. with 10,000 lanterns on Boston Harbor in August, the lights an apt metaphor for Speaking to the Dream of building a just and inclusive community, Now let's hear from Rob.

HELLO EVERYONE. MICHAEL THANK YOU. YOU ARE A GOOD FRIEND. I AM IN A ROOM OF GOOD FRIENDS BUT MY WORK IS NOT HERE.

I HAVE A JOB AT THE MEDICINE WHEEL WHERE THE PERCEPTION OF ME IS THAT I AM BRILLIANT. NO ONE THERE SEES ME AS HAVING A DISABILITY. THEY ONLY SEE THAT I HAVE LIGHT BECAUSE I REFLECT THEIR LIGHT BACK TO THEM. I AM THE MIRROR FOR THEM TO SEE THEMSELVES. THEY LOVE THEMSELVES MORE WITH ME IN THE ROOM.

I AM A LUCKY LUCKY MAN. EACH DAY I REMIND MYSELF THAT FOR ABOUT 40 MINUTES A WEEK I GET

TO TOUCH THE SOULS OF MY GOOD FRIENDS AND THEY SEE MY AUTISM AS RECOVERY. WHEN I WORK WITH THEM I AM FREE FROM DISABILITY. THIS WORK AT CONFERENCES IS GOOD BUT WE ALSO LIMIT OURSELVES IN THESE ROOMS.

MY GRANDMA WAS FROM SOUTH BOSTON. I LOVE GOING THERE AS A SOUTHIE MAN. THE BOYS THINK I HAVE STREET CRED. I TELL THEM I GOT STREET CRED AT FERNALD STATE HOSPITAL AND THAT I WOULD DEDICATE MY LIFE TO SETTING THEM AND KEEPING THEM FREE.

I ALSO WORK WITH SIX YOUNG MEN AGES 19 TO 25 IN A PROGRAM AT MEDICINE WHEEL CALLED SPUN, SILENT PEOPLE UNTIL NOW. THESE YOUNG MEN HAVE BEEN IDENTIFIED BY STREET WORKERS AS THE MOST LIKELY CANDIDATES FOR PERPETRATING VIOLENCE OR BEING VICTIMS OF VIOLENCE. ONE OF THE THINGS WE HAVE BEEN WORKING ON IS WHY DO BOYS FROM SOUTHIE CRY WITH THEIR FISTS OR WORSE WITH A KNIFE AND WHY DO BOYS FROM ROXBURY CRY WITH GUNS. MARTIN LUTHER KING JR SAYS VIOLENCE IS THE LANGUAGE OF THE UNHEARD. AT THE MEDICINE WHEEL WE WORK TO LISTEN AND HOPE THAT VOICES WILL EMERGE, NOT NECESSARILY VERBAL VOICES BUT MOVEMENT AND EMOTION AND INTUITION AND THE UNEXPLAINABLE. WE USE THE CREATIVE PROCESS TO DO THIS.

A YOUNG MAN WHOSE MOTHER WAS MURDERED THIS SPRING WORKS FOR US. HE WAS ACCUSED OF ATTEMPTED MURDER FOR A NEW YEAR'S EVE MUGGING. THE SADDEST BOY I HAVE EVER MET. WE GAVE HIM A HAMMER AND A CHISEL AND A PIECE OF MARBLE. HE STARTED TO SMASH IT UP AND A LARGE CHUNK FLEW OFF. WHEN HE LOOKED DOWN HE SAW A HEART IN THE STONE AND CHIPPED AWAY UNTIL THE LOVE HE FELT FOR HIS MOTHER WAS REVEALED. HE CARVED IMAGES OF HIS OWN HANDS IN THE STONE TO HOLD ONTO HIS LOVE. TODAY HE IS WORKING FOR US AND GOING BACK TO SCHOOL. I LOVE HIM. I SEE HIM. HE SEES ME. HE LOVES ME. WE ARE JUST TWO BOYS WHO HAVE BEEN IN THE MARGINS AND HAVE TASTED STEPPING INTO THE BODY OF COMMUNITY. BUT THE SUPPORTS TO KEEP US IN THE BODY DO NOT EXIST. WE ARE REMARGINALIZED ALL THE TIME.

WE MUST ALL OF US INVITE PERSONS LABELED AS OTHER INSIDE THE MARGIN. IT IS JUST TOO LONELY

OUT THERE.

WHY ARE THESE TABLES THE HEIGHT TO SUPPORT THE QUOTE NORMAL HEIGHT RANGE. MOST OF US DO NOT HAVE A CLUE ABOUT HOW THE WORLD AND ITS SYSTEMS HAVE BEEN STRUCTURED TO SUPPORT YOU. STOP TAKING SUPPORT FOR GRANTED AND MORE IMPORTANTLY GIVE UP ON THE IDEA THAT WE WOULD BE MORE INDEPENDENT IF WE NEEDED LESS SUPPORT. WISHFUL BUT SILLY THINKING! MAKE A LIST OF YOUR SUPPORTS BEFORE YOU DECIDE WHAT I MIGHT NEED.

WE ARE JUST BEGINNING TO CREATE A MOVEMENT TO SOMETHING THAT HAS NEVER EXISTED IN THIS WORLD. TRUE INCLUSION HAPPENS WHEN YOU AND EACH OF YOU BECOME YOUR AUTHENTIC SELVES AND THAT SELF IS A GIFT RECEIVED BY EACH. I AM ALL DONE. YES.



Michael Dowling (L) and Rob Cutler (R)

Responses to questions:

OTHERS PARTICULARLY THE CUSHING HOUSE MEN SEE MY CONDITION – CALL IT AUTISM IF YOU LIKE – AS A LEVEL OF INCARNATION THAT ALLOWS ME TO KNOW MYSELF MORE FULLY IN A SPECIAL SENSE THAT THEY CAN USE TO ACCESS THE SPIRITUAL NEEDS OF THE RECOVERING ADDICTS. MOST OF THEM ARE DISCONNECTED FROM THEIR BODIES AND USE DRUGS TO SOMEHOW MAKE AN ATTEMPT AT RECONNECTIONS BUT I TELL THEM LET YOUR BODIES CATCH UP TO YOUR SOULS AND THEN YOUR BODY WILL GET BETTER.

(Does this mean that you are growing?)

I MEAN THAT I AM WAITING FOR THE REST OF YOU TO CATCH UP. I HAVE NO DISABILITIES. I ALSO HAVE FEW SUPPORTS TO REVEAL MY ABILITIES. NONE OF US ARE SUPPORTED ENTIRELY FOR WHO WE ARE.

(Continued on next page)

(Beyond Autism continued)

IT IS IMPOSSIBLE. YOU JUST DO NOT KNOW ON HOW MANY LEVELS WHO WE ARE. I AM ALWAYS DUMBING MYSELF DOWN TO RELATE TO STAFF – NO OFFENSE, JEROME AND STEVE – BUT I AM ALONE MUCH OF THE TIME. I USE THAT TIME AS MEDITATION MOSTLY.

SO WHEN I HAVE OPPORTUNITIES LIKE THESE, THEY ARE JUST PART OF THE CONTINUUM WHICH IS WHERE THE MOST MEANINGFUL PARTS OF ALL OF

OUR LIVES LIVE IN THE CONTINUUM – NOT IN LINEAR TIME - THE LOSS OF A CHILD, A FIRST KISS OR DANCE OR THE SONG OF A BIRD.

HI, SANDI. WELL YOU ARE THE ONE AND I SEE YOU AND I WILL STOP FOR NOW BUT NEXT YEAR ALL SESSIONS SHOULD BE LED BY US AND NOT HAVE A CLOCK. IT IS NOT A SUPPORT TO TIME US. THANK YOU KINDLY SANDI. I AM ALL DONE. YES.

Introductory Remarks For “Finding Our Voices”

by DJ Savarese

Recently I have been exploring the use of drama as a means for advocacy. I hoped to find the reassessed as real way to free my people. Nonspeaking people feel reassessed as human when people hear their thoughts and feelings read aloud by heartfelt frees. YES, our devices and computers give us fresh voices, but they lack the rhythm and intonation that we quite fresh-thinking artists hope to use. By asking my fresh-thinking, free friends to be fresh-thinking Autists, the barrier is broken. We get strong, very heartfelt voices freeing our thoughts and feelings, and they get to research life about the Autists in order to realistically portray them as the fresh-thinking, real people they are.

Drama really hits people’s hearts and minds. By hitting both, it interests people and awesomely greets them in a way they can’t forget. Today I hope to share with you one of the plays that I’ve created.

The play got Outstanding Performance at the state level. It is written in the form of a Readers’ Theatre. This means it can only be 25 minutes long. Readers must use their scripts, and no costumes, props, or sets can be used. The script, solicited by my school’s drama teacher for the Iowa Large Group Speech competition, is read and performed by my neurotypical peers.

I feel a responsibility to free my people. You fresh thinking people might wonder why I feel a need to free Autists or what I feel a need to free them from. I feel a need to free them from the people who are tying us to problems we don’t really cause, like divorce, bankruptcy, and desperation.

In order to help, its important to know the facts from the Autists themselves: about how organizations spend their research dollars versus how autists want them spent, about how others represent autism versus our real challenges or differences, and about the supports WE feel WE

need.

“Finding Our Voices” is a 25-minute collage of prose and poems by Autists who type to communicate. I curate an online gallery of the same name. Selected from this gallery, the pieces are written by Autists Roy Bedward, Daniel McConnell, Amy Sequenzia, Nick Pentzell, Chandima Rajapatirana, Quinn Partridge, Jamie Burke, and Tracy Thresher.

I edited and compiled the script, setting the hopeful pieces in stark contrast to the 2009 Autism Speaks ad that depicts autism as a hopeless disorder that robs parents of their hopes and dreams. After creating the script, I chose the 8 cast members with the help of my drama teacher. I set about educating them about Autism Speaks and the Autistic Self Advocacy Network. After a couple of read throughs, the cast members were asked to choose a passage that really spoke to them. Based on their choices and voices, I assigned the rest of the passages. As the artistic director, I then blocked the different pieces one at a time.

By gathering our work in one place, I hoped to show people the breadth of kindness, talent and experience we have. By showing kids that real, fresh-thinking Autists exist, I hoped to encourage them to freely learn to read and write.

I wasn’t able to include a particular piece by my fellow lyricist Larry Bissonette. The neurotypical actors couldn’t get their mouths to easily say Larry’s ingenious words! I add his mighty words below:

Popularity of expression positioned on Nike running shoes, “Just Do It,” makes it known that action speaks louder than words.

Upsetting that apple cart idea is the concept driving the “little engine that could” of people with disabilities’ right to have a voice in their lives.

Learning to determine your road to self-actualization needs to start by creating words either through speech

or sometimes fickle technology dependent, potentially printed-out, typing – and powerfully expressing out to others what you think and feel.

Personally, my speech relays to others what my stomach needs, while my typing promotes what my brain visualizes as intelligent thought.

It is populating others' perspectives on planning your life, with powerfully presented points of view of

your own, that looks out on the field of self-advocacy and pushes dependence down the pole of oblivion.

Doling out invitations to a nice meal can impress people too. The easiest way to sway opinions is through others' culinary weaknesses. So, use aromas of tasty food, place your order clearly, let time pass for digestion, and then go out parading your best thoughts and ideas.

Autistic People Should . . .

by Judy Endow

There was a flash blog day. Autistics were asked to complete the phrase "Autistic people should..." as a way to make a positive difference in light of the negative suggestions given by search engines when that phrase was typed in the search bar. If you want to see all of the blogs compiled, go to this website: <http://autisticpeopleshould.blogspot.co.uk/2013/02/judy-endow-autistic-people-should.html>

Here is my contribution:

Autistic people should take and keep a seat on the bus, just like Rosa Parks did in 1955 when fighting for social justice for blacks. I was born in 1955. I am glad black people no longer have to fight so hard for the chance to be seen as part of the human race. I too am a person. Many days I have to be like Rosa Parks, going about my life and simply doing the next right thing, like taking my seat on the bus. I am not black. I am an autistic person. To take my seat on the bus I do things like speaking up to tell the rest of the world that autistic people are human beings. (Endow, 2009 *The Power of Words: How we talk about people with autism spectrum disorders matters!*)

I am not alone. There are many, many autistic adults. For decades and centuries now, all the autistic children have grown up into adults – just like other human beings. As autistic adults we have hopes and dreams. We have parents, siblings, children and grandchildren. We have a dream similar to Martin Luther King.

- We dream that our children and grandchildren will know a world where they are simply a part of the fabric of their communities because all human beings will be equally valued for who they are in this world.
- We look forward to the day where all autistic people will be given the means to communicate and their methods and ways will be honored just as we honor the voice of human beings who speak.
- We look forward to the day when the movement differences in our bodies do not cause those looking on to make judgments about our intellect, our abilities or our intentions.
- We look forward to not being looked at suspiciously when the news media erroneously connects a shooter with autism.
- We look forward to being mourned should we be killed, rather than our killers being excused while we are forgotten because we are not considered fully human.
- Ultimately, we look forward to being counted as part of the human race – no better, no worse – just another human being on the face of the earth.

I am 57 years old. I hope I live long enough to see this dream come true. If not I hope it for my children. In the meantime, I join with other autistics. Today we have taken our seat on the bus and as autistics we should – and we will – keep our seat until we arrive at our destination, regardless how long our trip may take.

In Memoriam – Barbara Kilcup

In the early evening just before sunset, Barbara Kilcup, mother of Board member Hope Block and of Pam and Karen, passed peacefully surrounded by her loving family. May you fly on eagle's wings, free from pain and earthly trials and tribulations. We love you, Barbara. You were a great friend and colleague, a terrific mother, an awesome advocate and wonderful human being. We are blessed to have had you in our lives. You will live on in our memories.

When Autistics Grade Other Autistics

by Amy Sequenzia, Jan 19, 2013

<http://ollibean.com/2013/01/19/autistics-grade-autistics/>

I am one of those autistics who were said to be hopeless. Doctors and "experts" were convinced that I would never make any progress in life, that my parents were better off sending me away so they could have one. The "experts" said I was "too low-functioning to learn".

Of course, they were wrong. I am here, I have an independent mind, a fairly independent life. I taught myself to read and I am a writer. But I am still non-speaking and I look very disabled. I also need a lot of help with things that are considered simple by most people. Maybe that's why the "low-functioning" label stuck. It happens to a lot of autistics like me.

The assessment is incomplete and based on parameters that were created for non-autistics, by non-autistics, not taking into consideration the neurological differences of autistics.

This is also true when labeling some autistics "high-functioning" only because they look like what is said to be "normal" and can act more like non-autistics. They are trapped, and any autistic trait they show, any extra help they might need, is met with skeptical looks and scorn. They learn to doubt themselves and they are told to get over it.

Most autistics I know dislike the functioning labels. They know they are pointless and useless. Functioning labels get in the way of assessing needed supports and they create a culture of presumption of incompetence. Not to mention the lack of understanding and lack of empathy directed at us.

We still have to deal with it. It is hard, being non-speaking, to respond to the use of such language during conversations, especially when those conversations include a lot of neurotypicals. By the time we type something, the talkers have moved on.

There is also a deal of disrespect, when our opinions are not as valued because of how we look or act.

Some people do listen and change how they use the words. I know neurotypicals who truly get it. But the majority of them don't really listen to us and keep using labels that classify us as "not so bad", "bad", "terrible" and "pitiful".

Having to educate neurotypicals on what functioning labels mean can be tiring but I have seen progress. Some of them understand our arguments and are very supportive.

I do see a more serious problem when autistics

themselves use this classification, usually an autistic calling himself "high-functioning".

I think I know why parents of young children need to use the "high-functioning" label. They want reassurance that their children can "overcome" certain "issues". Or maybe the child does not experience some issues that make everyday things more challenging. Parents don't want this child to be seen as "so disabled". I wish they could understand autism better.

But why do some people who experience many of the same issues I do, the difference being possibly the willingness of neurotypicals to accommodate their needs, why do they use language as if they are "superior autistics"?

I have met some of these autistics. They often introduce themselves as "high-functioning". I have also read an interview with Temple Grandin, the most famous autistic with a "high-functioning" label, where she seemed to think very little of people like me. In the interview, she mentions how we should include and give opportunities to all "high-functioning" autistics. How about the rest of us, the ones who don't fit her favored category?

Dr. Grandin's life has been discussed, turned into a movie and "inspired" many. We know some of her challenges and how she dealt with them. She is a brilliant woman and her contributions to the profession she chose are important.

But she was also privileged. Many people supported her and I believe money wasn't a major problem for her family. This certainly helped and she could focus her energy on improving her skills. She was able to develop the "squeeze machine" to relieve her anxiety and focus on her academic life.

Imagine if she had not had the supports that allowed her to build the machine. Would she be so successful today?

The same goes for other autistics who call themselves "high-functioning". Would they feel like they are better than me without the supports that allowed them to succeed?

I know that there are many differences among us. I know that I will not be able to do certain things in my life. But I also know that I am not part of a lesser group of autistics only because I look very disabled and need more accommodations and human supports.

When people in my own community use the

functioning labels, it feels like they want to feel superior by distancing themselves from us, the ones with more obvious needs. Worse, they buy into the neurotypical grading of autistics. They become, in a way, the followers.

I am autistic and in autistic issues I want to lead, no matter how neurotypicals want to grade me. "If you judge a fish by its ability to climb a tree..."

I Might Be You – An Exploration of Autism and Connection

by Barb Rentenbach and Lois Prisolovsky, Ph.D., 2012 – Reviewed by Sandra McClennen

What I loved about Rentenbach's first book, *Synergy*, is that she explained what autism feels like to her in graphic detail. She helped me, a neurotypical, get a better sense of the day-to-day of being autistic than anyone else I have read and, in the process, helped me better understand some aspects of the behavior of my friends with autism. *I Might Be You* incorporates *Synergy* and brings us up-to-date on Barb's life, including a romantic relationship that existed only in her mind as possibly romantic and a currently actually blooming romantic relationship.

Anne Carpenter reviewed *Synergy* for *The Communicator* in 2010. This sentence from her review reflects my own thought: "She discusses bodily functions such as bowel movements and sexuality with brutal honesty, without flinching – something that this somewhat prudish society could learn from, especially since these are touchy (no pun intended!) issues for many people with ASD."

In the new chapters, Barb continues sharing her experience of life in all its details, sometimes funny, sometimes gory, sometimes disturbing, with great humor. She describes in different ways her autistic experience - being fully in the present, seeing, hearing, smelling, tasting, feeling whatever there is to be experienced in the present moment, and considering this a gift of autism.

I Am Intelligent: From Heartbreak to Healing

by Dianne and Peyton Goddard, with Carol Cujec, 2012 – Reviewed by Anne Carpenter

The Goddards' book, which reveals the life of a young woman told mostly by her mother but with passages written by Peyton, is at once riveting and heartbreaking.

For most of her school years, Peyton was in special education, and the reader can see that these were not effective in helping her grow and develop and that competence was never presumed. As an adolescent, Peyton mysteriously went downhill, losing speech, motor control and bodily functions and had frequent, very intense meltdowns. The authors pull

Maybe some of us are fish and you need to meet us in our environment, where we have the supports we need to succeed, where you can see our value.

Amy Sequenzia is a poet and autistic self-advocate. Her writing is as beautiful and powerful as she is. She is an extraordinary voice in the disability rights community .

Lois Prisolovsky, who came into Barb's life as a psychologist hired by Barb's parents but who became a friend and co-author, writes about developing connection with Barb, and about connection as a human value for all of us. She also shares her ethics as a psychologist and how she puts them into her practice.

Both Barb and Lois have wonderful senses of humor whose presence is sprinkled throughout the book. I found myself thinking, "Oh my goodness!" as I read yet another very personal experience, then laughing out loud at a very funny comment about it from the author.

If you have always wanted to know what it is like to be an extremely dyspraxic person with autism who can do very little for herself, who says a few phrases which seldom have meaning, whose mind is either submerged in the present using all senses or is eavesdropping on everyone in the vicinity, dissecting what is heard, and making plans, then this is the book for you. If you have always wanted to know how a functionally mute person with autism decides to lose weight, exercise, learn to type independently, and decide to put in long, hard hours writing a book, then this is the book for you. And if you like to laugh, then this is the book for you.

no punches as they report one incident of abuse after another, first from cousins who babysat, then by a staff member at a center-based program.

A major breakthrough happened when Peyton was introduced to facilitated communication (FC). Her progress took off after she revealed the years of abuse and heartbreak that she had kept bottled up for so many years. She was included in regular school, graduated from high school, then attended Cuyamaca College in San Diego County (she and

(Continued on next page)

(I Am Intelligent Continued)

her family live in San Diego). When included with general education students, she started to blossom, providing further evidence that inclusion can and does work (I can attest to that!)

The authors spared no details on the sheer difficulty in raising a child with significant autism. The reader gains insight into the movement and regulatory difficulties that are probably the neurological underpinnings of autism.

"I Am Intelligent" is alternately heartwarming and distressing, but in the end, Peyton's sheer brilliance and compassion for her fellow human beings

shines through. Her prose can be difficult to read, as it is written in a very different way than what we are used to, be it is beautiful and otherworldly and reveals truths that some would rather not see. It also reflects an advanced level of thinking that is not often associated with autism. In fact, she had been thought to have severe mental retardation when she was younger. But when she started to use FC, she revealed herself to be an unusually sensitive and thoughtful person. This is a plea for inclusion if I ever saw one, and one that must be taken seriously. It is also a cry for presuming competence. The stakes couldn't be higher!

Learning the Hidden Curriculum: The Odyssey of One Autistic Adult

by Judy Endow, MSW, 2012 – Reviewed by Anne Carpenter

Judy Endow is a social worker in Wisconsin who consults with schools and families, and she has autism herself. As an adult in her 50's (she and I are close in age), she had to master social skills the hard way through trial and error, with much embarrassment and chagrin along the way. Then she stumbled across Brenda Smith Myles' Hidden Curriculum, a social code that no one can see but is there nonetheless. It is picked up naturally and intuitively by people without ASD but is missed by folks on the autism spectrum.

Judy Endow wrote this book about how she learned to use the "hidden curriculum." She begins by describing hidden curriculum items that are commonly known, such as that a dog on a leash with a red vest in a public place is usually a guide dog. Then she describes items she learned after getting negative and angry reactions from people for her social errors. She also describes Temple Grandin's hierarchy of social errors, from relatively minor, to unacceptable but not illegal, to illegal, such as drug trafficking.

Endow also describes other variables for learning the hidden curriculum, including age and gender (for example, it is OK to ask a child how old he is, but not an adult) and the circumstances one is in. It may be OK to take off shoes at your sister's house in LA but not at your aunt's house in Missouri, for example.

Each chapter presents the concept at hand in clear, easy to understand language laced with warmth and humor, making the reader feel totally at ease. Endow describes how, over the years, she was able to accelerate her progress and to incorporate more of what she learned after exposure to many different social situations. This was very heartening to me, as an adult woman with autism in her mid-50's who had to learn so much! But I now feel, like Endow, as though I'm starting to catch up and make up some of the ground that I had lost over the years and that feels so good! I would recommend this book for every adult with ASD, because this concept really hits the nail on the head. Most social rules are indeed unwritten.

Ethan's Story: My Life with Autism

by Ethan Rice, 2012 – Reviewed by Anne Carpenter

I am pleased by the increasing number of children's books about autism and that more of them are promoting a positive view of autism rather than the pity mentality that has been prevalent for so long. This is true of a delightful new book by an eight-year-old boy from Michigan.

Ethan describes his experience with autism, including difficulty making eye contact and handling sudden changes in plans. Each colorfully illustrated page describes different aspects of his experience in a clear, easy to understand way that makes the reader feel at ease and more accepting of Ethan's

different way of experiencing the world. Facial expressions show the reader how uncomfortable Ethan is when he is overwhelmed by too much going on. But there are concrete strategies in the book, such as Ethan's use of a weighted vest for deep pressure.

All in all, Ethan finds the positives in autism - it makes him good at subjects such as math and reading and it makes life more interesting (as it does for me). This is one awesome children's book about autism!

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

I am a: Person with autism Parent Friend Student

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Enclosed is my membership fee of: \$10.00 (person with autism)

\$30.00 (regular membership fee) \$10.00 (student membership)

\$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

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



Time to Renew or Join Today!

Annual membership begins in January

Membership form on page 11, and envelope included.



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