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THE COMMUNICATOR

A Publication of the Autism National Committee



Autism National Committee 2011 Conference

Autism Without Limits

Friday and Saturday, Oct. 21-22, 2011
Burbank, California

Join the Autism National Committee's annual conference and experience a shared vision through positive approaches. This conference will offer

- Analysis of key issues in autism from a human and civil rights perspective.
- Networking opportunities with individuals with autism, family members, and professionals who are at the frontier of social change.
- The AutCom Bookstore featuring the most progressive titles and authors in the field of autism.

Keynote Presentations

Sue Rubin - Autism Abounds Making Life Difficult, but Autism Also Makes Life Interesting

Anne M. Donnellan, Ph.D. (Professor, Director, USD Autism Institute) - Rethinking Autism: How Sensory-Movement Differences and Disturbances Affect People with Autism and their Stories. Professor Donnellan will address sensory-movement issues which challenge people with the autism label and often confuse those who love, care for and/or study them. This perspective is not meant to create another diagnostic category. Rather, it suggests

that our "assessment" of people with autism is based on our experience of them, not necessarily their experience. Greater understanding of the lived experience of autism may help to shift the emphasis from "control" to providing "accommodations" to better support those with the autism label.

Stephen Hinkle (title to be decided)

We want this conference to be as comfortable as possible for people on the autism spectrum. All food events will include a gluten-free, casein-free option. There will be a "crash" room with incandescent lighting.

We are working on getting CEUs for California professionals.

For Conference registration and hotel information, see the **registration form** on page 11. Conference Room Rate: \$120 (includes tax).

To make your reservation online, go to the AutCom website (www.autcom.org) and use code ATOATO.

If you prefer to reserve your room by phone, call 818-843-6000 and mention AutCom Conference to guarantee this rate.

Parking will be \$6 per day whether or not you are staying overnight at the hotel. Tell the parking attendant that you are attending the AutCom Conference.

Register Soon!

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Web Site: www.autcom.org



Mike Hoover

PUBLIC POLICY AT THE STATE AND LOCAL LEVELS

by MIKE HOOVER

INTRODUCTION

I AM MIKE HOOVER FROM BOULDER, COLORADO. I LIVE IN MY OWN APARTMENT AND I WORK IN A BREWERY. I NEED TO HAVE YOU LEARN WAYS YOU CAN BE A VOICE FOR CHANGE IN PUBLIC POLICY.

I NEED TO TELL YOU ABOUT THINGS TO DO, HOW TO GET SUPPORT TO DO THEM, HOW TO PREPARE, HOW TO GET PEOPLE TO LISTEN, HOW TO GO TO THE TOP, AND HOW TO HELP CAMPAIGN.

BOARDS AND COUNCILS

FIND A BOARD OR COUNCIL THAT INTERESTS YOU, ASK HOW TO APPLY TO BE ON THE BOARD, GET SOMEONE TO ATTEND WITH YOU. IF YOU WANT TO SERVE WITH THAT GROUP, GET THE PERSON TO GO ONE TIME WITHOUT YOU TO EXPLAIN HOW THEY NEED TO ACCOMMODATE YOU. BOARDS TO LOOK FOR INCLUDE SERVICE AGENCIES, ARC, TASH, AND NON-DISABILITY GROUPS.

THINGS TO ASK FOR

REQUEST THE AGENDA IN EMAIL, THE HELP OF A GROUP MENTOR, THAT YOU BE ASKED BEFORE THE GROUP MOVES TO THE NEXT TOPIC BECAUSE TYPING TAKES TIME, THAT YOU MAY GO EARLY TO GET SETTLED IN, THAT YOU MAY TAKE SENSORY BREAKS, THAT PEOPLE TALK ONE AT A TIME, THAT PEOPLE WAIT WHILE YOU ANSWER (NOT KEEP ON TALKING AND NOT TO INTERRUPT YOU), AND FOR ANYTHING ELSE THAT WILL ASSIST YOU IN PARTICIPATING.

THINGS TO INCLUDE AT MEETINGS OR PRESENTATIONS

BRING IDEAS AND INFORMATION LIKE WEBSITES; TELL THEM HOW THEIR GOALS AFFECT PEOPLE YOU KNOW; TELL THEM HOW OTHERS BEST ACCESS CONFERENCES, EMAIL, AND NEWSLETTERS; TELL THEM HOW YOU CAN HELP.

CONSIDER THESE THINGS: COSTS AND SCHOLARSHIPS, TRAVEL, BAD MEETING SPACE SUCH AS LIGHTS, NOISES, BRIGHT SUN.

MY FIRST BOARD

I GRADUATED FROM PARTNERS IN LEADERSHIP IN 1994. I WAS ASKED BY LES REED IF I WANTED HELP TO BE ON THE COLORADO TASH BOARD. I HAD A HARD TIME AT FIRST. THEY DID NOT TAKE TURNS. THEY TALKED TOO FAST. THEY MOVED ON WITHOUT SEEING I WAS TYPING. BUT LES ENCOURAGED ME AND THEM, AND I AM STILL ON THE BOARD. RIGHT NOW I AM HELPING PLAN FOR THE DECEMBER TASH CONFERENCE IN DENVER.

THE COUNCIL

I AM WITH **WATCH OUR WORDS COLORADO** (www.wowcolorado.org). I HAD THE CHANCE TO GIVE A PROPOSAL AT THE COLORADO DEVELOPMENTAL DISABILITIES COUNCIL TO GET A GRANT FOR WOW. I HAD TO GIVE ANSWERS TO TOUGH QUESTIONS, BUT WE GOT THE GRANT, AND I GOT A CALL ASKING ME TO APPLY FOR THE COUNCIL. I DID AND WAS APPOINTED BY THE GOVERNOR FOR TWO TERMS, AND NOW I AM BACK AGAIN.

THE PUBLIC POLICY COMMITTEE

I LOVED LEARNING HOW LAWS ARE MADE DURING PARTNERS IN LEADERSHIP. I GOT TO GO TO THE STATE CAPITOL FOR A DAY. I DECIDED TO JOIN THE COUNCIL PUBLIC POLICY COMMITTEE. WE MEET IN THE STATE CAPITOL. I LOVE GOING THERE. I LOVE GETTING TO LEARN ABOUT BILLS AND DECIDING IF

I LIKE THEM. I HAVE GIVEN TESTIMONY TO HELP STOP BAD BILLS. I HELPED GET GOOD ONES PASSED. I LIKE KNOWING I MADE A DIFFERENCE.

REGISTERED LOBBYIST

LEARN IF YOUR STATE REQUIRES YOU TO REGISTER TO BE A VOLUNTEER LOBBYIST. IN COLORADO I WENT TO AN OFFICE IN THE CAPITOL AND SIGNED A FORM, SHOWED AN ID AND GOT A CARD. I SIGN IN AT THE HEARING ROOM TO GIVE TESTIMONY. IF I CAN NOT GO, I WRITE THE COMMITTEE MEMBERS TO TELL THEM HOW I FEEL ABOUT THE BILL.

THE AUTCOM BOARD

I WAS INVITED TO APPLY FOR THE AUTCOM BOARD SO I APPLIED. I GOT ELECTED AND SERVED SIX YEARS. NOW I AM AN ADVISOR TO THE BOARD. I THINK I NEED TO HAVE YOU THINK IF YOU WANT TO DO IT. THEY NEED TO HAVE GOOD IDEAS.

THE ELECTIONS

REGISTER TO VOTE AND THEN VOTE. TRY TO ATTEND PUBLIC SESSIONS TO MEET THE CANDIDATES. LEARN ABOUT BALLOT INITIATIVES AHEAD OF TIME. TAKE SOMEONE WITH YOU. LAWS GIVE YOU THAT RIGHT. I USE MAIL IN BALLOTS.

THE AGENCY CONSORTIUM

THE COLORADO DD COUNCIL IS HEADING A GROUP OF ORGANIZATIONS INTERESTED IN DISABILITY TO WORK TOGETHER FOR SYSTEMS CHANGE. I THINK I NEED TO HAVE THEM BE MORE ACTIVE IN MAKING DECISIONS. I NEED TO TELL THEM HOW I FEEL ABOUT THE THINGS WE HAVE DONE SO FAR.

CAMPAIGN

GET TO KNOW A GOOD CANDIDATE AND HELP GET THEM ELECTED. I OFFERED TO HELP A GOOD LEGISLATOR RE ELECTED. I MARCHED WITH HER IN A LOCAL PARADE. I WILL DELIVER FLYERS TO A PRECINCT. I LIKE YARD SIGNS, TOO. MY APARTMENT DOES NOT PERMIT IT BUT WE PUT ONE IN MOM'S YARD.

THE ELECTIONS

AFTER NEW PEOPLE ARE ELECTED WRITE TO THEM WITH YOUR IDEAS. BE SURE TO GET ON THEIR RADAR RIGHT AWAY. MEET THEM, CALL, OR WRITE. TELL THEM THANK YOU FOR GOOD THINGS THEY DO.

BE A VOICE IN YOUR COMMUNITY AND STATE

TELL PEOPLE THINGS THAT ARE GOOD. TELL THEM THINGS TO FIX AND HOW. GET ON A BOARD. MAKE CHANGE HAPPEN.

ONE CHANGE I MADE LAST YEAR

A SCHOOL WANTED AN EXCEPTION TO A STATE LAW THAT WOULD LET THEM USE A LOCKED TIME-OUT ROOM. I WENT TO THE HEARING WHERE THE BILL WAS INTRODUCED. I HAD MY TESTIMONY WRITTEN AHEAD OF TIME. I SIGNED IN, THEN GOT TO GO FIRST. I TOLD THE COMMITTEE WHY THE RESTRAINT WAS A BAD IDEA. THEY THEN ASKED ME QUESTIONS, AND I TOLD THEM HOW IT MIGHT AFFECT ME. I HELPED GET THE BILL STOPPED.

WHEN THE GOVERNOR SIGNED THE BILL TO REQUIRE DISABILITY REPRESENTATION ON BOARDS AND COMMISSIONS, I GOT THE PEN.

USE YOUR VOICE EITHER SPOKEN OR WRITTEN.

Donations to AutCom

Donations in memory of Paul Bakeman's mother, Kathryn Bristol Bakeman, (1911 - 2010), Grandmother and ally, whose advice to all of us was "Life is uncertain; eat dessert first." The donors are Rena Gans, Barbara Cutler, and the Bakeman family.

AutCom Donors 2010-2011

Nancy Alar
Anonymous
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Judi Barta
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Ruth Myers, M.D.
Sue Pratt
Phil Schwarz
Marcia Spray
Emily Titon
Kay Weaver
Fleur Wiorowski
Songdon Yu



Stephen Powell & Rob Cutler

AUTCOM CONFERENCE IN MILWAUKEE, OCTOBER 2010

by Rob Cutler

I AM HAPPY TO BE ASKED TO PARTICIPATE AT THE CONFERENCE WITH JACOB PRATT AND MIKE HOOVER. JACOB IS A GOOD MAN AND I AM GLAD WE BOTH GET TO TYPE. MICHAEL HOOVER IS A GREAT MAN WHO, LIKE ME, GOES TO THE STATE HOUSE. HE IS OUR WESTERN REPRESENTATIVE WHO DOES WORK LIKE ME. WE ARE HUMAN BEINGS WHO WANT TO BE TREATED WITH RESPECT. AUTCOM GETS IT. I WANT TO ADVOCATE TO HELP PEOPLE WHO CAN'T COMMUNICATE TO HAVE A VOICE.

I GO TO THE STATE HOUSE TO ADVOCATE FOR MY FRIENDS WHO CAN'T GO. WE NEED TO STICK TOGETHER BECAUSE THERE IS STRENGTH IN NUMBERS. WE CAN'T BE QUIET WHILE OTHERS GET THE MONEY. I WANT LEGISLATORS TO KNOW THAT WE DO NOT NEED OUR SERVICES CUT. WE NEED TO ALL BE AS ONE.

I KNOW MONEY IS TIGHT RIGHT NOW BUT MY FRIENDS NEED TO FEEL SAFE, AND IF OUR PROGRAMS ARE CUT WE WILL ALL LOSE OUT. I ASK TO KEEP US SAFE.

I GO TO THE STATE HOUSE TO WALK THE HALLS AND GET THE WORD OUT TO OUR LEGISLATORS ABOUT SAVING OUR SERVICES AND ALSO TELL THEM PLEASE CLOSE FERNALD AND GIVE FREEDOM TO THE PEOPLE WHO ARE KEPT THERE. THEY (the legislators) HAVE BEEN BRAINWASHED INTO THINKING FERNALD IS A NICE PLACE AND I KNOW THAT TO BE FALSE. WE NEED TO PROTECT OUR PROGRAMS THAT ALLOW US TO LIVE IN THE COMMUNITY.

THERE IS A WORLD HERE BEYOND THE WALLS OF FERNALD. I AM HAPPY THEY ARE CLOSING FERNALD. YES

WITH THE RIGHT SUPPORTS WE CAN BE GOOD CITIZENS IN THIS WORLD. WE ARE LOOKING FOR A HAND, NOT A HANDOUT. YES

WE NEED PEOPLE TO HELP US VOTE. WE MAY NEED A RIDE OR WE MAY NEED SOMEONE TO EXPLAIN WHAT VOTING IS ALL ABOUT. IF WE ARE NOT TOLD, WE CAN'T VOTE. THEN OUR RIGHTS ARE BEING DENIED. WE CANNOT BE LEFT OUT OF DECISIONS THAT AFFECT US. IT IS CORRECT TO SAY "NOTHING ABOUT US WITHOUT US." WE NEED TO BE HELPED AND I DO NOT THINK THAT IS TOO MUCH TO ASK FOR.

SOME PEOPLE WANT US TO BE PUT AWAY AND QUIET BUT MY MOM HAS TAUGHT ME THAT WE NEED TO BE SEEN AND HEARD. WE NEED TO MAKE A NOISE. YES

I GO TO THE POLLS WHERE I AM KNOWN AND RESPECTED. I GO TO CAB MEETINGS [Citizen Advisory Board of the Mass Dept of Developmental Services] AND ALSO ADVOCACY GROUPS. REMEMBER, WE CAN VOTE IN OUR ALLIES AND VOTE OUT THOSE OPPOSED TO US. I WANT TO THANK YOU ALL AND REMEMBER TO GET OUT AND VOTE. WE CAN CHANGE THE WAY THE WORLD SEES US. YES.

Praise for Life

by Faith Crandall
Mystic, CT

Life is up, life is down.

Life is square, life is round.

Life can be good.

Life can be bad.

Life can be happy.

Life can be sad.

Life is varied as you can see

But with patience and prayer it becomes

What you want it to be.

I like this life. It is good.

It is interesting, too.

I am wanting to share my world

To all who need to change theirs too.

Life is terrific and praise the Lord

And look to be his prophet to serve.

(I have been writing through the use of facilitated communication for 15 years because of being disabled and unable to speak. I reside with my mom who is also a writer. Mom and I make our home in Mystic, CT.)



Jacob Pratt

Public Policy Advocacy by Jacob Pratt

At AutCom in Milwaukee this year I was honored to be a member of a distinguished panel of FC users, each of whom had experience in public policy advocacy. Mike Hoover began the panel with an excellent description of how to get involved. I came next, describing my own activism. Rob Cutler typed an eloquent and passionate piece about both his activities and a plea for why people affected by public policy must teach those in power about the realities of our autistic lives and how we are affected by policy decisions - especially bad ones. Here are the things I spoke about.

Issues I began with a list of issues that concern me today. I think we need to be aware of what is going on in our legislatures because all it takes is a loud-mouthed parent or a group that has their interests, not ours, in mind for a really bad bill to become law. These are the current hot topics from my perspective.

- ABA instead of other teaching tools. Just

because someone is a certified behaviorist does not mean they have a clue about autism. Trust me, hearing 'good job' only increased my echolalia even though the people saying it thought they were rewarding me. That is just one example of what leaders need to hear so they don't allow only one intervention to be covered by insurance.

- Getting the right support. The legislature and government officials do not walk in our shoes. They need to understand that sometimes our need for support increases, and it should not take an act of God to increase funding and services at those times. They need to realize that they waste more money when people hang on to excess money in their individual budgets "just in case."
- Use of restraints and aversives on people like us and how difficult it is when someone like the guy in Massachusetts who has a nephew at the Rotenberg Center truly believes it is helping this poor guy when his so-called behaviors are no more challenging than mine. Positive behavior supports work, but most of us need facilitated communication or good sensory diets if we are that self-injurious or aggressive, and the rest of us need a better quality of life so we have no need to be that angry, hurt, or frustrated.
- Funding transportation. I am in love with a beautiful woman with autism who lives in another state. I think we should be able to take the public funds that are used to support each of us across state lines. Then either she can move to Connecticut, I can move to Rhode Island or we both can move to Pennsylvania to share a house with my best friend. Right now, this is unlikely, yet people without autism can live wherever they want.
- Personal issues. People with autism have the same list of personal issues as everyone else. Should there be national health care for everyone? Should we increase fines for reckless driving? Should we provide condoms to people who test positive for HIV or AIDS?
- Budget cuts. I understand the need for fiscal conservatism, but why is it always human services that they go after first?

State Legislators. I told the audience at AutCom that I have already addressed these issues with my state legislators. I have testified and also spoken to them or their staffs in the halls of the state

Continued on next page

(Public Policy Advocacy, continued from page 5)

capitol building, in their offices, and at various forums in the community like legislative awareness events. I've been seen both in Connecticut and in Massachusetts.

Due Process and Litigation. Passing laws is not the only way TO INFLUENCE PUBLIC POLICY. SOMETIMES YOU HAVE TO REQUEST due process to get an agency to follow their own rules, and sometimes we need to sue them. My parents had to go to due process in Regional School District 15 to get me a good inclusive education where I learned to type. When they lost, they had to take the school district to court. Four other families were also fighting for their child's right to be included with nondisabled peers and all became a class action suit. That's how I became a named plaintiff in the P.J. inclusive education lawsuit against the Connecticut Department of Education and Regional School District 15. My mother also had to go to many administrative hearings against the Connecticut Department of Mental Retardation to get the service I needed to live in my community, attend school, go to church, etc. Although I could never have done these things on my own, it was important that my parents knew how to affect public policy this way because others besides me benefitted.

Voting. It's election time as I write this. You have the right to vote. Learn what the candidates' positions are on the issues important to you. Don't just vote because your parents were Republicans or Democrats and don't just stay home.

AutCom and other groups' legislative advocacy. I am on the Board of Directors for AutCom and TASH New England. Through both groups I am informed about activities at the national and local levels so I can help form the group's response and know what I need to do as a citizen to address the public policy issues that these groups address. These groups have the same values I have, so it is usually more a matter of style in how issues are addressed. Sometimes education and a gentle approach can work. Other times strident we-won't-tolerate-compromise positions must be taken.

Teaching L.E.N.D. fellows. Another way to advocate is to teach others to advocate. I have presented at local Arcs, People First groups, and at other meetings to teach people what's possible and necessary

around such issues as inclusive education, the right to type to communicate, and self-determination. My proudest time has been training future leaders in leadership education in neurodevelopmental and other disorders that they have to stop maintaining the status quo and speak up for change.

National Level Letterwriting. Lastly I spoke about how important it is to write to your federal congressional representatives and senators even if they don't appear to listen. The more letters or emails they get about issues of concern to us, the more likely they are to pay attention to those issues and why a particular position must be taken. Here are two examples of not listening for your entertainment. They are Connecticut's Senators' responses to identical letters sent to Connecticut's two U.S. Senators about the Senatorial hold on Ari Ne'eman's appointment.

As you can see, Senator Dodd (letter #1) was more intent on talking about his agenda than responding to me, whereas Joe Lieberman's (letters # 2 & 3) speak or don't speak for themselves. On the other hand, the responsive office of Congresswoman Rosa DeLauro had a different constituent-minded approach (no reply was sent). Although I got no direct response from her, I did get the letter I needed from the Selective Service for my FAFSA application. Here is the letter I wrote to her (letter #4).

I am hoping this leads to public policy change as more of us choose to go to college and can't apply for federal financial aid because no one thought to register us for the draft as required by law. Apparently, the selective service likes to make that determination on their own, and FAFSA doesn't want to give loans or grants to people it thinks are draft dodgers.

I hope this is helpful to readers about the many ways they can get involved in advocating for public policy changes that affect all of us in general and those of us with autism in particular.

Jacob Pratt's Letters

Letter #1 from U.S. Senator Christopher Dodd

May 20, 2010

Dear Mr. Pratt:

Thank you for your recent letter concerning the nomination of Ari Ne'eman to a position on the Interagency Autism Coordinating Committee (IACC). It was a pleasure to hear from you.

As your United States Senator, it is my job to work to implement federal policies that will effectively address the interconnected challenges that our state

Jacob Pratt's Letters (continued)

and nation face. These challenges include the global economic crisis, continuing threats to our national security, and our over-reliance on foreign fossil-fuels to name just a few. Real solutions require taking into account the ideas, opinions, and concerns of all citizens in order to ensure that we can achieve a consensus as to the best course of action.

I would like to express my appreciation to you for sending me your thoughtful opinions, questions and concerns. These comments and ideas are important to me and provide essential insight on how best to represent all the people of Connecticut. Please be assured that as I fight to address these immense challenges, know that your voice has been heard and taken seriously, and that I will do all in my power to continue to advocate for you every day.

Again, thank you for contacting me. If you would like to stay up to date on my actions in the United States Senate, and around the State of Connecticut, please visit <http://dodd.senate.gov> to view video, press releases, speeches and other important resources you may find useful. Please do not hesitate to contact me again if I may be of assistance to you in any way.

Sincerely, CHRISTOPHER J. DODD, United States Senator

Letter #2 from U.S. Senator Joseph I. Lieberman

From: correspondence_reply@lieberman.senate.gov
 To: asdi-ne@comcast.net
 Date: 30 Mar 2010 00:40:28 -0400
 Subject: Correspondence from Senator Lieberman

Dear Friend:

Thank you for visiting my Contact Center and sharing with me your comments on the important issues I am addressing in Congress. Your message has been received; you will be receiving a response to your concerns as soon as our review and research have been completed.

I hope you will continue to visit my web site at <http://lieberman.senate.gov/> for updated news about my work on behalf of Connecticut and the nation. Please contact me if you have any additional questions or comments about our work in Congress.

Sincerely, Joseph I. Lieberman
 UNITED STATES SENATOR

Letter #3 from U.S. Senator Joseph I. Lieberman

Here is the follow-up letter nearly two months later:

From: correspondence_reply@lieberman.senate.gov
 Subject: Correspondence from Senator Lieberman

May 19, 2010

Mr. Jacob Pratt
 197 Eddon Drive
 East Haven, CT 06512-1050

Dear Mr. Pratt:

Sincerely,
 Joseph I. Lieberman
 UNITED STATES SENATOR

Letter #4 - Jacob Pratt's letter to U.S. Congresswoman Rosa DeLauro

Dear Congresswoman DeLauro, I am a 32 year old man who has severe autism but is unable to get financial aid for college because everyone thought I was retarded. Instead of filing for me with the selective service no one did. I wrote to them – a copy is attached – following their rules and expecting to hear from them in the promised 6-8 weeks. I did not. I appeal to you to have the selective service agree that my failure to enlist was not my fault but my guardian's and the Dept. of Mental Retardation staff and that I need clearance from them before my FAFSA can be reviewed and my financial aid determined. As it is I had to withdraw from a second class this summer because I don't have enough money to pay out of pocket or any credit to get any other kind of a loan. Thank you for your assistance. I authorize you to deal with my mother, Chris Pratt, who is my guardian. My friend and colleague Dr. Linda Rammner who is also a constituent of yours has been helping me complete all the applications. You may speak to her, too. Jacob Pratt.

"When I was very little, I just thought I was another little boy. Then, when I was diagnosed with autism, I just thought that something was different but did not know what about me was different. Something about me was very different than normal people my age."
Stephen Hinkle, from his article in *Sharing Our Wisdom*, available from the AutCom bookstore. Stephen will be a keynote speaker at the 2011 AutCom Conference.

Review by Anne Carpenter

Real People, Regular Lives: Autism, Communication & Quality of Life by Sally Young

Ever since the 1990's when Facilitated Communication (FC) burst into the forefront of education for people on the autism spectrum, it was controversial. No one wanted to believe that the highly sophisticated and articulate pronouncements issuing from hundreds of keyboards, letter boards and computer screens were coming from people whose behavior often included rocking, making noises and aggressiveness, as that flew in the face of prevalent thinking about autism. It was hard to believe that people who were so severely affected could be so articulate. Dr. Sally Young's brilliant and compelling new book, *Real People, Regular Lives: Autism, Communication & Quality of Life*, explores this phenomenon and its ramifications for society.

The book begins with a short introductory chapter, giving a brief explanation of autism and a short discussion of communication and quality of life, then goes into the real heart of the book, narratives of adults with autism who have used FC and are telling their own stories. They include Barbara Rentenbach, Chammi Rajapatirana, Nick Pentzell, Sarah Stup (who wrote *Do Si Do with Autism*), and several others. In their communications, they express the sheer frustration resulting from their sensory processing difficulties and their movement differences, making life more difficult, because they engaged in behaviors that were out of their control. But something wonderful happened when their facilitator touched their arm and their fingers hit the keys. They felt in control for the first time in their lives! New worlds opened up for them, and they were able to explain why they needed to engage in certain behaviors that were deemed "challenging" but that they didn't need to do anymore.

For example, when Barb Rentenbach used FC, she no longer broke her glasses, as she no longer felt the need to do that; she also got better glasses and her vision improved markedly. The stories are so heartfelt and compelling that it would be hard for anyone to be as skeptical about FC after reading them. In Part III, the author explores in great depth issues relating to FC and communication including skepticism which, in a few situations, has been justified, as it has been found that a very few facilitators are doing the communication, not the person with autism her or himself. The validation

studies done in the early 1990's and the Frontline show, *Prisoners of Silence*, broadcast in 1993, all threw a bucket of cold water over facilitated communication. Though many questions have since been raised about the approach and quality of these studies, many agencies stopped allowing their clients to communicate.

Other themes that are discussed include sensory and movement differences, relationships, emotions, FC at school and in the workplace, building protective worlds against a harsh environment, behavior, personhood and spirituality. These themes go into real depth and bring the experience of autism closer to those who do not experience it.

I was awestruck by the book. The narratives were beautifully written and revealed powerful insights into what autism was like for each person. One can see that these are intelligent minds here; no IQ score can possibly measure what these people are thinking, feeling and doing.

FC needs to be looked at more closely, and it should be given another chance. We owe this much to people with autism who would otherwise be voiceless in institutions, group homes and sheltered workshops, now that the 21st century is well underway.

Review by Anne Carpenter

How to Talk to An Autistic Kid by Daniel Stefanski

Daniel Stefanski is a thoroughly likeable boy of 14, who has autism and embraces his autism in such a positive way that the reader is caught up in that. In this charming little book, he describes what he experiences in the way of communication difficulties and sensory processing issues, including not hearing everything that a person says to him, taking figures of speech too literally, and not respecting another person's space. He explains autism very thoroughly; he describes the difficulties with understanding the body language of others and how one often gets "stuck" when obsessing about a special topic of interest (his is Australia).

Instead of taking a negative approach, he suggests ways for peers to help him, such as giving gentle reminders about moving further away, suggesting that he talk about something else or inviting him to play a game such as chess or a video game or to make something together. In this way, peers can make friends with him and learn more about autism at the same time. Daniel feels that being "different" is just fine and that having autism doesn't preclude living a happy life with friends and

family.

I just love the feel-good message of this book. The illustrations are a soothing mix of black, white, gray and aqua, and they add real charm to the story. The author emphasizes respect and compassion when talking to a kid with autism, and he wants others to see more of the positive ways that autism affects a person and to accommodate the difficulties, instead of criticizing or teasing, which is so often the case.

Daniel Stefanski was adopted from an orphanage in Bulgaria when he was four years old and lives with his family in Indiana. This is one of the best children's books on autism that I have seen. It reflects a more positive view of autism in the face of continued lack of understanding and misinformation about autism that is still going on today. This book will help the children and teens of today become the compassionate adults of tomorrow, as they learn how to relate to the increasing numbers of people being diagnosed with ASD. Kudos to you, Daniel!

I LOVED THE MOVIE

by MIKE HOOVER

I LOVED THE MOVIE "WRETCHES AND JABBERERS". I HAVE SEEN IT TWICE AND IT IS GREAT FOR THE MESSAGE IT SHARES ABOUT PEOPLE WHO DO NOT SPEAK. I NEED EVERYONE TO SEE IT. LARRY AND TRACY GO TO SRI LANKA AND JAPAN AND FINLAND TO VISIT OTHERS WHO USE FACILITATED COMMUNICATION TO TYPE. IT IS FUN TO HAVE THE PEOPLE SITTING TYPING TO THE OTHERS AS THE JABBERERS SIT QUIETLY BY IN THE RESTAURANT. I LOVED HAVING TRACY THINK OF THINGS TO ASK THE BUDDHIST MONK ABOUT LIFE'S PURPOSE. I LOVED THAT LARRY HATED SUSHI BECAUSE I DO, TOO.

I THINK I NEED FOR FC USERS TO GET THE WORD OUT THAT THE METHOD IS VALID. I THINK I NEED TO THANK THE COUNCIL FOR SUPPORTING THE ADVOCACY WORK OF WATCH OUR WORDS. THE AUTISM SOCIETY OF COLORADO HELPED PROMOTE THE MOVIE IN THEATRES AROUND THE COUNTRY IN APRIL. IT WILL BE ON DVD SO IF YOU MISSED IT, BE SURE TO GET THE DVD. THANKS TO BETTY LEHMAN FOR ASKING ME TO ANSWER QUESTIONS AFTER THE MOVIE IN WESTMINSTER APRIL 2. I GOT TO BE INTERVIEWED AT 9 NEWS THE DAY BEFORE.

THE BEST THING IS THE EXCITEMENT OF BEING PART OF OPENING MINDS TO NEW COMMUNICATION AND OPENING DOORS TO NEW POSSIBILITIES IN PEOPLE'S LIVES.

(Editor's Note: The movie will be available on DVD sometime this summer.)

Judge Rotenberg Center Update

AutCom has been working with others to try to shut down the Judge Rotenberg Center (JRC), a Massachusetts private school that uses painful electric shocks for discipline. Despite several state and federal investigations, the school remains open. JRC is paid by school districts to educate and care for children with a wide range of conditions. Some are autistic or schizophrenic, while others are troubled teens whose rebellious behavior was too much for the public school system to handle. But regardless of their students' mental or physical capacities, the school has a one-size-fits-all treatment for about half of its students: electric shocks.

Earlier this spring, school founder and executive director Matthew Israel announced he was stepping down as of June 1, part of a plea bargain to spare himself jail time. Israel agreed to resign and to undergo "five years of pre-trial probation to settle charges accusing him of interfering with an investigation..." The investigation in question is a 2007 incident in which someone pretending to be a JRC supervisor called the school and ordered administrators to shock two of the teens. The administrators gave one teen 29 shocks, and the other 77.

Massachusetts attorney general Martha Coakley indicted Israel on charges that he ordered staff to destroy video footage of the incident. Unfortunately, his departure doesn't necessarily mean that things at the school will change. There will be additional checks in place to make sure incidents similar to the 2007 event do not recur, but the shock devices will still be allowed. Even though Israel is gone, the Department of Justice still has an open investigation of the school for violations of the Americans With Disabilities Act.

"My life without communication was 24 years of living hell. Imagine yourselves sitting in your seats and having your thoughts constantly interrupted by thoughts of terror, your own voice sounding like a thunder of garbled words being thrown back at you, and other folks screaming at you to pay attention and finish your task. You find your body and voice do unusual things, and you realize you aren't in control. People are screaming at you to stop the aggression, and they stick a raisin or lemon juice in your mouth, depending on your response. Now add to this that you cannot talk... maybe a few words...but nothing consistent with language. With all this in mind, welcome to the world of a person with autism who is also non-verbal." **Jenn Seybert** from her article in *Sharing Our Wisdom*, available from the AutCom bookstore.

Principles of the Autism National Committee

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

Moreover, I oppose the use of institutions to separate people from their communities, and deprive them of dignity, freedom and the level of independence they can achieve in supportive community living; the use of procedures involving pain, humiliation, deprivation, and dangerous drugs as a means to alter and control individual's behavior; the increasing use of bizarre technology to control self-injurious and aggressive behavior; the widespread ignorance of the basic social and communicative needs of people with autism; and the widespread disregard for the individual's unique, basic and human needs. I object to programs which disregard the skills, preferences and basic human needs of the people they serve, and I believe that there is no longer need or any justification for using painful and abusive procedures.

AutCom Membership Form

Name: _____

Street Address: _____

City: _____ State: _____ Zip Code: _____

Telephone and/or fax (optional) _____

Email

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

I am a: _____ Person with autism _____ Parent _____ Friend _____ Student

_____ Professional (field) _____

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

AutCom (Autism National Committee) 2011 Annual Conference

Autism Without Limits

October 21-22 - Los Angeles Marriott Burbank Airport Hotel - Burbank, California

For hotel reservations call 818 - 843 - 6000 and ask for the AutCom conference reduced rate

More information at www.autcom.org

Jay Nolan Community Services is honored to be an active supporter of Autism National Committee

Entire Conference (includes breakfasts, lunches & Friday dinner/program) - Food preferences? See box at bottom.

Individuals with autism: Number of participants _____ x \$125 = \$ _____

Family members/support/students: Number of participants _____ x \$205 = \$ _____

Professionals: Number of participants _____ x \$305 = \$ _____

Friday day session only (includes breakfast & lunch) - Food preferences? See box at bottom.

Individuals with Autism: Number of participants _____ x \$75 = \$ _____

Family members/support/students: Number of participants _____ x \$115 = \$ _____

Professionals: Number of participants _____ x \$170 = \$ _____

Friday Dinner and program only (in addition to single day sessions) - Food preferences? See box at bottom.

Number of participants _____ x \$40 = \$ _____

Saturday day session only (includes breakfast & lunch) - Food preferences? See box at bottom.

Individuals with autism: Number of participants _____ x \$75 = \$ _____

Family members/support/students: Number of participants _____ x \$115 = \$ _____

Professionals: Number of participants _____ x \$170 = \$ _____

Donation to support attendance of individuals on the autism spectrum: \$ _____

Total Registration Fee & Donation: \$ _____

Cancellations, less 10%, before October 11. No refunds after that date!

Participant Name/Names: _____

Address: _____ City: _____

State: _____ Zip: _____ Phone: _____

E-Mail address for confirmation: _____

Select method of payment. See mail-in and fax instructions below. Online registration is at www.autcom.org

___ Check ___ Purchase Order (Enclose copy of purchase order)

Visa/MasterCard/AMEX #: _____ Exp. Date: ____/____/____

Name on card (Please print) _____ Signature _____

Mail or Fax payment and registration form to:
Jay Nolan Community Services
AutCom - Autism Without Limits
PO Box 9604, Mission Hills, CA 91346-9604
Fax (818) 365-9202 - Email: al@jaynolan.org

Indicate number of registrants for special meal requests:
Gluten Free = _____ Casein Free = _____
Gluten Free/Casein Free = _____ Vegetarian = _____

Autism National Committee

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



2011 Conference Information Inside

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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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