

THE COMMUNICATOR

A Publication of the Autism National Committee



## Introduction

We are very excited to bring you this issue of The Communicator, with timely articles on coping with the pandemic, dealing with unpredictability, and the need for digital equity. We also have a Statement of Solidarity, a Call for Action, poems, book reviews, news, resources, and more. We hope you have made it through this difficult year safely. Thanks to all our contributors. We wish everyone a very safe, productive, and joyful year in 2021!

# Save the Date! AutCom Conference

Volume 27, No. 1 - Winter 2021

October 15-16, 2021

Concord, New Hamshire

# A Call to Action!

**AutCom** joins the **Alliance Against Restraint and Seclusion** and other advocacy organizations in a **Call to Action to support the Keeping All Students Safe Act, which has numerous sponsors in Congress.** Autistics and other students are at risk of injury, trauma, and death from restraint and seclusion every day in our country. These practices must end. Your support is needed. Please contact your Senators and Representatives to encourage them to support and pass this law. For more information, see the link below.

"The Keeping All Students Safe Act would make it illegal for any school receiving federal taxpayer money to seclude children and would ban dangerous restraint practices that restrict children's breathing, such as prone or supine restraint. The bill would also prohibit schools from physically restraining children, except when necessary to protect students and staff. The bill would better equip school personnel with the training they need to address school-expected behavior with evidence-based proactive strategies, require states to monitor the law's implementation, and increase transparency and oversight to prevent future abuse of students."

https://endseclusion.org/2020/11/19/keeping-all-students-safe-act-call-to-action/

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Renew Your Membership! (See the form on last page)

## Season's Greetings!

On behalf of AutCom's Board of Directors, I want to wish you all the best holiday available to you. I know how difficult this year has been for everyone. I can't help but be hopeful that 2021 will bring us strong federal guidance and an effective vaccine. We all need to do our best to survive until it's available to everyone. Please do not celebrate the holidays with anyone outside of your household, and wear masks as if your lives depend on it (they do!).

I am also feeling optimistic about AutCom's conference, October 15-16, in Concord, NH. We hope it will be completely safe by then to emerge from our hidey-holes and attend. We plan to have a significant focus on intersectionality and achieving equity. Many of us have multiple intersecting identities, for example, a Black autistic woman, a White transgender autistic man, or someone who is both autistic and visually-impaired. Autism is not a monolith. There are diverse populations within our community, and we want to be supporting, understanding, and appreciating these differences. Our dedicated Board members are urging everyone to share your stories and learn from each other. I hope you will join us in Concord in October.

I also urge you to visit our Facebook page (Twitter is coming!) and "like" and "share" what you read. Please send us suggestions that might help us reach more people.

AutCom is a grassroots, all-volunteer organization, and we rely solely on memberships and donations, so if you can encourage your family and friends to join, it will help us keep the cost of our conferences down.

Happy holidays to everyone, and here's hoping our national nightmare will soon be over.

Yours, Lisa Keller, AutCom President

## AutCom's Statement of Solidarity

When we are given no voice, we are stripped of our power and the ability to self-direct our lives. We stand with those who have been powerless because of a power structure that does not seek out and value all diversity. We can give our best when all lives matter because black lives matter, and powerless voiceless people everywhere matter as much as those in power.

## Get Out of Town by Lisa Keller

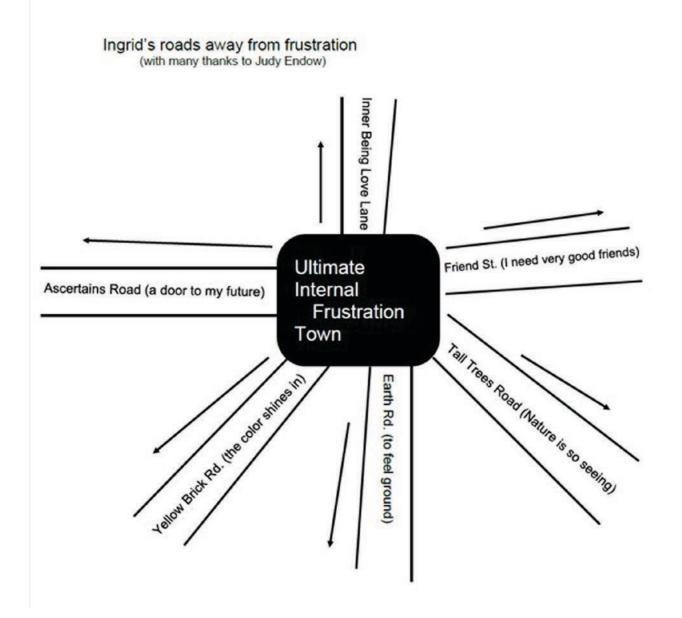
In my never-ending quest to understand autistic neurology, I recently bought Judy Endow's latest book, Thriving Autistically. For those of you unfamiliar with Judy, she is an extraordinary autistic woman who is a mental health counselor and a former AutCom Board member. She is often called by schools to troubleshoot the "behaviors" of autistic students. Her own autistic neurology provides her with great insight into that of her students. She is quick to point out that every autistic individual is different, and she cautions against overgeneralization.

Judy writes about her struggles as a young girl whose frustrations often led to meltdowns. She writes, "...I was using my literal, concrete, think in pictures style to serve me along with my need for sensory system regulation." She envisioned a town that she calls "Ultimate Internal Frustration," and the routes that could lead her away from this troubled place. She gave them names, such as Kaleidoscope Way, and Lake View Road, evoking scenes of color and peace. I was recently seeing one of my clients, Ingrid (wearing masks, of course), and asked her to imagine her own Ultimate Internal Frustration town. With her permission, I am sharing the town with its roads away from frustration that she envisioned. Drawing on imagery from her life, she named the streets and then explained why she chose the names. The images come from her hikes in local forests (Tall Trees Road) and recent landscaping work hauling bricks and wheelbarrows filled with dirt (Yellow Brick Road and Earth Road).

Ingrid's explanations (in parentheses) were as compelling as the names of the roads themselves. Ascertains Road was initially puzzling to me, until she typed "because I see it as a door to my future." I googled "ascertains" and found the definition: "find something out for certain; make sure of."

A graphic representation of Ingrid's Ultimate Internal Frustration Town follows.

"Ultimate Internal Frustration Town" is in the center (a black box with rounded corners with the text in white lettering). Five roads (with arrows pointing away from the black box) lead out of town. Their names and explanations, starting at the top and going clockwise around the box, are these: Inner Being Love Lane; Friend St. (I need very good friends); Tall Trees Road (Nature is so seeing); Earth Road (to feel ground); Yellow Brick Rd. (the color shines in); Ascertains Road (a door to my future).



## Digital Equity in the Time of Covid-19 by Cynthia Thielen and Alan Kurtz

Cindy: When the COVID-19 pandemic hit the United States, most people weren't used to the idea of staying home, but I was used to a certain amount of social isolation due to being autistic and living in a small town where it's hard to get around without a car. Before the pandemic, I was able to go into my office every day, talk to my coworkers, and get a chance to leave and go into the big world outside of my tiny apartment. Watching shows, playing video games, and coloring pages have proven to be good coping mechanisms. I often like using Instagram and other social media to share photos, so I'm happy that the outbreak hasn't changed that.

I've been able to visit with Mama every week or so, but I haven't seen a lot of people for the most part. Most days involving sitting at my kitchen table and meeting with my coworkers through Zoom, but it's good that I'm able to talk and visit with them. I was scheduled to travel with my supervisor and classmates in the New Hampshire/Maine LEND program to the Disability Policy Seminar in March. but we weren't able to go because of the virus outbreak. It was hard because I don't get the chance to travel often. Finding ways to interact with others is harder than it was before, and now I get a bit anxious when going out because I have no way of knowing if I'm going to get sick or not. Just a couple weeks before the shutdown, I found out that I have thyroid issues, and I found out that it's autoimmune within the last month. I'm also used to having Mama or a friend go with me for emotional support. Visitor limits have become a big issue for me and other disabled patients, and becoming sick during a pandemic makes me nervous, but I'm going to be okay, I hope. I don't know how long the outbreak is going to last, but I'm trying to think calm and peaceful thoughts.

I've been able to help my coworkers at the Center for Community Inclusion and Disability Studies at the University of Maine establish a Social-Undistancing committee so we can help people with disabilities who lack access to technology and are socially isolated due to COVID-19. I helped create tutorials so people can learn how to

use Zoom and Facebook Messenger. My favorite part is being able to host weekly Zoom meetings with clients from a local provider agency and help them find ways to connect with others. We've also hosted a virtual picnic as well as a virtual Halloween party. Participating in these meetings has helped me cope with social isolation because I've made new friends who I wouldn't have met otherwise. One of the highlights of our work was collaboration with the Maine Developmental Disabilities Council (MDDC) and their program, distributing iPads and providing technical support for their use. The program has been very successful. The MDDC found that those receiving iPads needed very little technical assistance in using it to connect with others.

Alan: Cindy, as with many autistic people, is very adept in the use of technology. In fact, Cindy is the go-to person in our office when we have Zoom questions. As she makes clear, her use of digital technology is one of the things that has helped her cope with the pandemic. Unfortunately, not every autistic person has the kind of access to technology that Cindy has.

My brother Bruce, for example, has enjoyed bi-weekly Zoom meetings with his far-flung siblings since April. Unfortunately, Bruce can only participate in Zoom meetings on days when a particular staff person is working at his group home. His use of digital technology to connect to others seems to be limited to our family Zoom meetings, telehealth, and formal planning meetings. Bruce's limited access to digital technology appears to be all too common.

The Social-Undistancing Committee, on which both Cindy and I serve, has found that limited use of technology is, in fact, quite common. Through our survey of adult providers in Maine and through our direct experience helping people get connected, we have learned a great deal about the obstacles to internet and social media access.

Those obstacles seem to be especially problematic for individuals supported in group residences. They include the following:

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- A lack of personal devices or regular access to devices;
- No personal internet account and limited access to agency accounts;
- Lack of funding for devices or for internet access;
- Lack of support and training in using software and apps;
- Perceptions that people lack the communication or cognitive skills to use technology;
- Limited technological expertise of professional support staff;
- Safety concerns of professional staff and guardians;
- Internet and social media access regarded as a low priority by professionals;
- Tendency on the part of agencies to use the internet to recreate the segregated programs (such as day programs) that have traditionally isolated autistics and others from the larger community.

For many, limited access to technology and support during this pandemic has amplified problems associated with a vast Digital Divide - a divide that marginalizes those lacking access to the digital technology on which most of us rely. Access to the internet and social media has become essential for people to participate in many communities whose movement to virtual environments has only been accelerated by our response to Covid-19. In 2020, access to digital technology has become more than a luxury. Its rapid expansion into all aspects of our lives, including the ways we connect with others, compels us to begin regarding it instead as a fundamental right. Unfortunately, many autistics, as well as other disabled people, fail to exercise that right because of limited incomes, insufficient funding, inadequate support, and paternalistic policies and attitudes.

Digital technology provides unprecedented opportunities for inclusion. That opportunity

will remain only an empty promise, however, unless we begin to achieve Digital Equity – or universal access to the digital technologies that most people now use for work, entertainment, social connections, education, gaming, shopping, and maintaining health and wellness. Failure to achieve Digital Equity, in an increasingly digital world, will lead inevitably to even greater levels of isolation and exclusion.

Cindy and Alan: There are a number of steps we think need to be taken to advance Digital Equity. First, training in using digital technology should be made available to people who currently lack those skills as well as to those who support them. That training needs to include instruction and support for participation in inclusive online communities. Second, we need to make digital technology universally available and provide information to autistic individuals, family members, and professionals about programs that provide or fund technology. Third, person-centered planning must be used to help teams identify specific steps they can take to ensure regular individual digital access. Finally our advocacy communities must begin to advocate assertively for digital access as a fundamental right.

To that end, we urge all members of our community to advocate for Digital Equity. We hope that the current pandemic, with all its negative impacts, can serve as a positive impetus for promoting universal digital access and for ensuring that autistics have new opportunities to participate fully in communities of their choice.

## **COVID-19 Vaccine Priorities**

Autistics and individuals with intellectual and developmental disabilities should be included in the group of high-risk diagnoses and prioritized for COVID-19 vaccination. As noted by the Autism Society of America in its joint statement with numerous advocacy organizations, "Individuals with autism and other developmental disabilities are at a greater risk for severe complications and death from COVID-19, especially if they have underlying health conditions or are living in congregate settings."

## Autism Society of America - COVID-19 Vaccine Statement

https://www.autism-society.org/news/the-autism-society-of-america-and-national-disabilityorganizations-encourage-the-autism-and-i-dd-community-to-be-prioritized-for-covid-19-vaccination/

## **NOW WHAT?**

# Unpredictability and Coping with the Pandemic by Anne Carpenter

Over the last few months, I have had to deal with something that is so difficult for many people with ASD, including myself – unpredictability, especially in major crisis situations such as the COVID-19 pandemic. I keep wondering when will this end? How will it end? Will there be a vaccine at the end of the year? Will I see my sisters for Thanksgiving and go to Sarasota for Christmas? In addition, I wonder how soon I will return to the Autism Society of Michigan office and go to the grocery store and get my hair cut again.

Because there are no answers to these questions, I and so many others are left to swim in a pool of uncertainty, not knowing when things will truly get "back to normal." So I've come up with my own ideas and strategies, the main one is being flexible about when things happen. I have been working at home and enjoying the flexibility of hours and not having to make the long commute to and from work. I have managed to get work done by breaking up the work day so that I work two-and-a-half hours, take a break for lunch and then work another two-and-a-half hours.

Because of this long period of isolation, I have been forced to deal with my anxieties and to find ways to work around them. I tell myself that this can't last forever and I have to figure out how to get to the office in a safe way once restrictions are lifted. I am now learning to "go with the flow" and take a wait-and-see attitude as this is a situation that has many moving parts.

To keep from feeling completely isolated, I have been having zoom chats with my sisters and my niece Jennie every Sunday and have also participated in other zoom meet-ups. In this difficult time, I am resolved to extract as much joy as I can and to stay positive as much as possible amongst the anger I am feeling about how poorly managed this pandemic has been and the sheer insanity of it all. I am starting to feel more grounded and better able to handle challenging situations such as not giving into temptation to buy impulse items but to focus on buying necessities such as groceries from Whole Foods delivered to my door and ordering paper towels and tissues from Amazon.

I have come up with some coping strategies that make the isolation more bearable. I have a weekly routine: work three days a week, then, on the other days, take an afternoon nap and a walk down a nice path to the local park listening to All Things Considered on NPR. I often watch the PBS News hour while cooking dinner, and I either watch Rachel Maddow at 9 or watch something on Netflix or Amazon Prime on my new Kindle Fire. I have found other ways to make this period more enjoyable such as watching TV in the evenings while sitting in my LED inflatable chair and changing the color of the light to suit the program. For example, I change it to blue when watching the first episode of The Crown on Netflix or pinkish purple when watching the Thursday night Coronavirus Town Hall on CNN. I like to listen to music or NPR on my new CD boombox with colored lights that pulse to sound.

But I miss hugs from friends and relatives, lunches and dinners with my friend Mary, two floors down, and movies with friends. I know that these things can't be done right now in the name of good public health, so I say to myself that I'll be able to do these activities again and that Thanksgiving and Christmas will bring back joy and wonder.

When I take this stance, I feel better knowing that I am doing fine with how I'm handling things. When things change, I can gradually shift to doing things differently. I'm amazed that I have been able to adapt. I wasn't sure how I was going to handle living in a pandemic of this magnitude, but I did a lot of thinking and reflection and that's what has helped so much. As for uncertainty, I will go by what Mom always said so wisely: "It's all to be discovered."



Yasmin Arshad

## **Finding Hope**

by Yasmin Arshad

Just when pain Stifles all my energy, And all I can do Is sleep... I find my hope.

The great wave Of blackness, That deep depression in which No stars reflect, Such is my sorrow. Suddenly a silver fish,

A flash of brightness: And with just One beat of my heart, A sliver of hope Returns.

Such is the suddenness Found deep in my soul Which swims to the surface And leaps in my heart.

#### My Birds By Yasmin Arshad

Bird of the dawn, Hope pours from your song! Every note sweet With promise renewed.

Bird of midday! Joy flies in your wake: Chasing the dreams Of freedom in song.

Bird of the evening, You coo to me softly; Answering my yearning With sweet sorrow in woe.

Bird of the night Brings my day to a close, Singing so sadly Of all that is gone.

Birds of the air, Carry forth my voice! Your songs. Your flight. Be my voice. Be my wings!

## Someplace Good and Deep Art / Poems by Daniel McConnell Reviewed by Sandi McClennen

"The art comes from my spirit and I want it to say I love people." Daniel McConnell opened his book with this statement, and wrote in his Introduction that "Autism is not a condition, it is a way of life." Sandy Whiteman, Healing Arts Specialist, who facilitated art sessions with Daniel, wrote in the Foreword, "He [Daniel] was empowered to choose colors, spread paints across a variety of surfaces and use objects to paint around, over, and print. Soon, his words flowed, as well."

Someplace Good and Deep, Art / Poems is a book of great beauty. On each two-page spread, a poem and a work of art are paired, with carefully selected titles.

An extensive Introduction includes information about Daniel and his thoughts on many aspects of his autistic life. (This information is a shortened version of Daniel's chapter in the book, Real People, Regular Lives by Sally R. Young, Ph.D., a publication by AutCom.) Daniel has been typing to communicate since 2007, when he was 23 years old. He completed his GED in December 2013 and is now working on a college degree at Western Technical College in La Crosse, Wisconsin, where he is an honor student and recipient of a poetry award. He wants to be a writer and to advocate for others like himself.

To see some of Daniel's art, to buy his book, to see a video of his life to date, and to contact him, visit his website: someplacegoodanddeep. com

Daniel selected one of the poems from his book to be printed in this edition of The Communicator.



Daniel McConnell

Artist of the Spirit by Daniel McConnell

I am an artist of the spirit that moves in me. The spirit is a force of hope and love. I want to help others, and I am Doing my best to be forgiving of all. I talk with words dear to me; They are in my heart. I dare to let them out When I feel safe. I am an artist who feels The pain of the world And wants to heal the sadness.

## **New and Exciting**

## **Elected**

The 36th District in Pennsylvania has elected autistic advocate, Jessica Benham, as State Representative for 2021-23. Benham has been active with the Pittsburgh Center for Autistic Advocacy.

**Happenings** 

## **Project LETS**

Project LETS is looking for folks with lived experience of madness, mental illness, Disability, and/or neurodivergence to join our facilitation team. Our facilitation team is responsible for planning, developing content for, and facilitating workshops + trainings on a variety of topics relevant to our work, to many different audiences (students, mental health providers, educators, organizers community members, etc.).

Apply:http://tinyurl.com/LETSFacilitate Questions? stefanie@projectlets.org

## Books

#### The Meaghan Report

A Penetrating Look Inside The Mind of Autism That Will Make You Question All That You Thought You Knew by Meaghan Buckley and Gail Buckley (2019) <u>FREE</u>.

http://www.grabgreatcontent.com/Free/THE\_ MEAGHAN\_REPORT.pdf

#### Real

By Carol Cujec and Peyton Goddard. "Inspired by a true story, Real speaks to all those who've ever felt they didn't belong and reminds readers that all people are worthy of being included." Publication date: February 2, 2021.

https://shadowmountain.com/product/real/

#### Someplace Good and Deep

By Daniel McConnell -- a book of art and poetry (2020).

https://someplacegoodanddeep.com/

## Spectrums: Autistic Transgender People in Their Own Words

Edited by Maxfield Sparrow (September 2020). https://www.ubcpress.ca/spectrums

#### Teaching Myself to See

By Tito Mukhopadhyay. "I continue to teach my eyes to see – as I realize seeing is an essential part of survival in a chaotic system called 'world' where things do not gather to simplify but scatter unto chaos." (To be published soon) Imprint: 3Ecologies Books.

https://punctumbooks.com/titles/teaching-myselfto-see/

#### Welcome to the Autistic Community

"We wrote this book for autistic people who want to learn what being autistic means... We also want non-autistic people to read the book. It can show you how to make life better for autistic people." <u>FREE</u> book by Autistic Self Advocacy Network. Download or read online.

https://autismacceptance.com/

## Videos

#### Camouflaging Distress

#ActuallyAutistic Suicide Risks with Lydia X. Z. Brown and Shain A. M. Neumeier — #SPSM Chat April 19th, 2020 (1:10:25; captions available) https://spsmchat.com/2020/04/19/camouflagingdistress-actuallyautistic-suicide-risks-with-lydiax-z-brown-and-shain-a-m-neumeier-spsm-chatapril-19th-2020/ (New and Exciting continued from previous page)

## **Toolkits**

#### **Communication First**

COVID-19 Communication Rights Toolkit with printable patient accommodations request form (in English, Spanish, simplified Chinese) https://communicationfirst.org/covid-19/

#### Green Mountain Self Advocates (GMSA)

Training packets, educational resources, and selfadvocate toolkits in plain language, all <u>FREE</u>. Know Your Rights (video): People with Disabilities Can Have a Supporter in the Hospital during COVID-19.

https://tinyurl.com/knowyourrights-disabilityvideo

#### Know Your Rights (booklet)

Bringing a Supporter to a Hospital or a Doctor's Office (co-produced with Autistic Self-Advocacy Network)

https://tinyurl.com/knowyourrights-booklet

#### Protecting the Safety and Health of Workers\_

(booklet) using OSHA/CDC guidance https://tinyurl.com/protectinghealthsafety-workers

#### A Self-Advocates Guide to COVID-19

Includes plain language information on nine different topics, each of which can be downloaded https://tinyurl.com/selfadvocates-toolkit

There are additional resources on the website of the GMSA: https://gmsavt.org/

## **Articles and Other Resources**

#### *First-Hand Perspectives on Behavioral Interventions for Autistic People and People with other Developmental Disabilities*

by Finn Gardiner. This report was commissioned by the Office of Developmental Primary Care, a program of the UCSF Department of Family and Community Medicine, and prepared by the Autistic Self Advocacy Network of Greater Boston with generous support from Alta California, Far Northern, Golden Gate, North Bay, Redwood Coast and San Andreas Regional Centers https://autisticadvocacy.org/wp-content/ uploads/2017/07/First-Hand-Perspectives-on-Behavioral-Interventions-for-Autistic-People-and-People-with-other-Developmental-Disabilities.pdf **Note**: You must copy this URL in it's entirety, and paste it into your browser.

### How Art Saved My Life During The Pandemic

by Amanda Porche, on The Art of Autism, Connecting through the Arts, June 3, 2020. "I know for a fact that others on the spectrum and people with mental health issues feel just as alone and hopeless as I do. I hope they will read this story and it will inspire them to paint."

https://the-art-of-autism.com/how-art-saved-mylife-during-the-pandemic/

## Supports for Problem Solving Informed by the Neurodivergent Community

https://autismlevelup.com/whys-not-sizesupports-for-problem-solving-informed-by-theneurodivergent-community-solvenotsize/\_

#### What is Police Violence?

A plain language booklet about anti-Black racism, police violence, and what you can do to stop it. https://autisticadvocacy.org/2020/06/police/

## **Our Autistic Lives**

Personal Accounts From Autistic Adults Around the World Aged 20 to 70+

Alex Ratcliffe, Editor – Jessica Kingsley Publishers

Reviewed by Anne Carpenter

Among all of the autobiographies, memoirs and essay collections by autistic adults that have been released over the years, this book stands out from the rest. It uses age as the framework. Divided into sections by age, starting with the 20s and ending with the 80s, it gives the reader an idea about how one's experience with autism can be affected by age.

Gideon-Sebastian, advocate, who diagnosed himself with autism at 21, then got a medical diagnosis at 22, discusses his obsessions, including Roman mythology and homeless people. Izanagi, who dreams of going to Japan, practices Aikido and lives in a Buddhist temple. Alex is a guard who says that he shouldn't be doing what he's doing because of his autism. People in their 30's include Laura, a police officer, and Annie, a teacher. The contributors describe their daily lives including morning and evening routines, sensory

processing difficulties, and their respective careers. Many of them have been married and have children from previous marriages as they have often had difficulties keeping the relationships going.

Some of the contributors have managed to find love later in life which is a real inspiration to me! I was fascinated by the sheer variety of individuals and lifestyle choices portrayed in this book, and I was struck by how many of the older writers seemed to be "younger" in their behavior and approach to life. The individuals who had children seemed more overwhelmed by all that responsibility, yet didn't seem to love their children any less. This is a real cross-section of autistic adulthood from different countries, including the US, the UK, Australia and Europe, and it should be on every reading list for those interested in all things autism.

## **Thumbs Up and Thumbs Down**

## Thumbs Up

\* Leading Disability Rights Groups File Amicus Brief Defending the Affordable Care Act in Supreme Court Case. "The American Association of People with Disabilities, the Disability Rights Education and Defense Fund, the Judge Bazelon Center for Mental Health Law and sixteen other leading disability rights organizations, represented pro bono by law firms Dentons and Baker Hostetler, filed an amicus brief with the U.S. Supreme Court highlighting the crucial health care protections that Congress provided for people with disabilities in the Affordable Care Act (ACA). The ACA prevented people from being denied coverage or charged more due to pre-existing conditions and made coverage of needed services available and affordable to millions of people with disabilities for the first time." The Supreme Court heard arguments on the case, California v. Texas, on November 10, 2020.

\* The Office of Special Education Programs (OSEP), within the U.S. Department of Education's Office of Special Education and Rehabilitative Services, which issued this Question and Answer (Q & A) document in response to inquiries concerning implementation of the Individuals with Disabilities Education Act (IDEA) Part B dispute resolution procedures in the current COVID-19 environment.

https://www2.ed.gov/policy/speced/guid/idea/ memosdcltrs/qa-dispute-resolution-procedurespart-b.pdf

\* The Significant Victory for Patients with Disabilities in response to a joint complaint brought by CommunicationFIRST and other organizations regarding Hospital No-Visitor Policies. On June 9, 2020, a Federal Civil Rights Resolution makes clear that hospital visitor policies nationwide must accommodate the need for in-person supports for

(Thumbs Up & Down Continued on next page)

### (Thumbs Up & Down Continued)

patients with disabilities who require it to benefit from medical care during the covid-19 pandemic.

https://communicationfirst.org/significant-victoryfor-patients-with-disabilities-in-response-to-jointcommunicationfirst-complaint-on-hospital-no-visitorpolicies/

\* Organizations who have worked to make virtual meetings and conferences accessible and welcoming to all during the 2020 coronavirus pandemic

## Thumbs Down

\*Attempts to eliminate the Affordable Care Act

upon which many millions of Americans depend, including autistics and other self-advocates, have continued to be a major concern.

\*Congress for delays in funding of the Heroes Act to provide much needed relief to businesses, organizations, and individuals during the ongoing Covid-19 pandemic, leaving many people in dire straits

\*The State of Florida, which continues to fail Arnaldo Rios-Soto, who is still waiting (since 2016) for proper, personalized, respectful supports, despite his family's ongoing efforts. To follow this case, follow his lawyer, Matthew Dietz on Twitter @dislaw.

## **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 individuals' 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.

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 communicator@autcom.org

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### The COMMUNICATOR Committee

Judy Bailey and Sandra McClennen Co-Editors

Doug McClennen, Barbara Cutler, Ed.D., Rob Cutler







## AutCom Annual Membership Form

Join any time. Renew each January (except for Lifetime Members).

Name				
Address				
City	State	_ Zipcode	Phone	
Email				
Newsletter by email or in print	ted form when avail	lable		
I want to Renew my mem	bershipB	ecome a membe	er	
I am a/an Autistic person	Family m	ember	_Friend	
Student	Professional (fie	ld)		
Enclosed is my membership fee of: \$10.00 (autistic person)				
\$30.00 (regular membership) \$10.00 (student membership)				
\$75.00 (supporting membership) \$500.00 (lifetime membership)				
I am enclosing an additio	onal \$	donation to	speed up the	good work!
As a donor, I wa	nt to be listed	_ by name	anonymous	Sly.
Send this form or a 3		an, AutCom Tre	easurer	Committee to
	AutCo	m Officers		
	Anne Carpen Judy Bai	ler, President ter, Vice-Presic ley, Secretary man, Treasure inen, Past-Pres	r	