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# THE COMMUNICATOR

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## Introduction

We hope that this newsletter finds you safe and well. Much in the country and the world has changed, at least temporarily, since we printed the Winter 2020 newsletter. We expect that you are actively working to cope with the current reality of keeping distance from others, staying home, and seeking ways to deal with each passing day. These new challenges, on top of the previously existing ones, make 2020 an especially tough year. We are still here, and we plan to keep going through this crisis and beyond.

In this issue, we have included more articles from AutCom 2019 Conference presenters, along with poetry, book reviews, resources, New & Exciting, and Thumbs Up & Down. We have added COVID-19 Resources, including links to informational, educational, and recreational sites (virtual tours and more).

This is our first issue published solely in an

electronic format. To honor physical distancing and safety recommendations, we decided to distribute it via email and online, rather than printing and mailing it. As always, you may share this newsletter online or by printing copies to use and distribute, as you wish.

As we plan for the next issue of the Communicator, we invite you to share your thoughts, reflections, and insights as you experience the weeks and months of the quarantine and associated difficulties. We hope you will share with others how you are reacting and managing, what coping strategies are helping or not helping, what advice or resources might be useful to others. Send your articles and poems—long or short—to us at [info@autcom.org](mailto:info@autcom.org). We encourage you to share your thoughts and experiences to help promote autistic voices, perspectives, and rights. Now, as always, you need to be heard.

## Help Protect Civil Rights of People with Disabilities

Your calls and emails to your two Senators and your Representative to Congress are very much needed at this time to protect civil rights of people with disabilities. Congress is working on the next stimulus bill which includes addressing three very important disability priorities. Here is the information you need:

1. The Secretary of the Department of Education wants to grant waivers allowing suspension of

IEPs. Disability advocates fear that once this is done, we will have a very difficult time avoiding abuse of waivers in the future. IEPs and special education services are a civil right. We cannot let any waivers be granted. Ask for the next stimulus bill to have a prohibition of the granting of waivers for IDEA by the Secretary of the Department of Education.

(Continued on next page)

### Inside This Issue:

- Page 2: New and Exciting
- Page 3: Gaining Control of Your Life after PTSD
- Page 6: Challenging Behaviors - What Works
- Page 10: Book Review: What your Child Needs
- Page 11: Protesting Shock Treatment
- Page 12: Education & Entertainment Resources
- Page 12: Poem by Yasmin Arshad

- Page 13: COVID & Disability
- Page 13: In Memoriam - Mel Baggs
- Page 14: Book Review: Fall Down 7 Times
- Page 15: Thums Up/Down
- Page 16: DJ UN Talk
- Page 18: Lisa Keller on MNRI

**Renew Your Membership! See the form on page 20.**

(Civil Rights continued)

2. The American Academy of Developmental Medicine and Dentistry (AADMD), a highly respected national organization, has issued a policy letter stating that because of limitations or behavior that may impact clinical care for individuals with intellectual and developmental disabilities, a family caregiver or agency personnel must be allowed to be with the person with a disability and to give information relevant to that individual's care to medical personnel. Ask that these reasonable accommodations be included.

3. AADMD has a second policy letter stating that "the presence of an intellectual or developmental disability must not be used as a factor for

determining life expectancy or quality of life and, furthermore, must not be used as an exclusion criterion for ventilator support or the allocation of other scarce medical resources. The same medical risk factors applied for other patients should be those considered for patients with intellectual and developmental disabilities." Ask for prohibition of discrimination in access to health care screening, testing, treatment, and ventilators based on disability.

Our website, [autcom.org](http://autcom.org), has these AADMD policy letters in full as well as additional information about disability priorities in the next congressional stimulus bill. Make your voice heard!

## New and Exciting

### Films

***The Reason I Jump*** - Sundance, 2020. "An immersive cinematic experience of nonspeaking autistic people across the world, *The Reason I Jump* is based on a book written by Naoki Higashida when he was just 13. The film follows a young Japanese boy on a journey through an epic landscape. As a maelstrom of thoughts, feelings, impulses, and memories affects his every action, he gradually discovers what his autism means to him, how his perception of the world differs from others', and why he acts the way he does—the reason he jumps." <https://www.sundance.org/projects/the-reason-i-jump>

Exclusive clip: "The Reason I Jump" explores neurodiversity through the experiences of nonspeaking autistic people from around the world." <https://realscreen.com/2020/01/23/exclusive-clip-the-reason-i-jump-to-take-on-neurodiversity-at-sundance-20/>

***Treasure All: Peyton Goddard and Autism***. An experimental animated film in a vertical format about growing up with autism, through the eyes and words of Peyton Goddard. "Treasure all, because great is each." (2:59) <https://leirighfilms.com/titles/treasure-all>

***Hale - the documentary*** (2019) - Oscar nominated film about early disability rights pioneer Hale Zukas. ReelAbilities Film Festival 2020. Available online on Prime.

<https://www.facebook.com/HaleTheMovie/>

TED Talk: Amy Laurent · TEDxURI - Compliance is Not the Goal: Letting Go of Control and Rethinking Support for Autistic Individuals

[https://www.ted.com/talks/amy\\_laurent\\_compliance\\_is\\_not\\_the\\_goal\\_letting\\_go\\_of\\_control\\_and\\_rethinking\\_support\\_for\\_autistic\\_individuals](https://www.ted.com/talks/amy_laurent_compliance_is_not_the_goal_letting_go_of_control_and_rethinking_support_for_autistic_individuals)

### Disability Rights Movement

***Crip Camp: A Disability Revolution*** (2020): Full Movie Online (and on Netflix). "Down the road from Woodstock in the early 1970s, a revolution blossomed in a ramshackle summer camp for disabled teenagers, transforming their young lives and igniting a landmark movement."

<https://bit.ly/2PPgwnr>

### Books

***Stim: An Autism Anthology*** by Lizzie Huxley-Jones (April 2020). A collection of stories, essays and art from autistic authors and artists. <https://unbound.com/books/stim/>

**COMING July 21, 2020 - *Spectrums: Autistic Transgender People in Their Own Words***, Edited by [Maxfield Sparrow](#), Jessica Kingsley Publishers.

### Blogs

Judy Endow blog - includes a new 8-part series, ***Autism and the Sensory System***  
<http://www.judyendow.com/blog/blog-list/>

### Toolkit

***Organ Transplantation and People with Disabilities: A Toolkit for State Advocates***. ASAN Unveils Toolkit for Advocates on Ending Discrimination in Organ Transplantation.  
<https://autisticadvocacy.org/policy/toolkits/organs/>

## Gaining Control of Your Life after PTSD

A Presentation by Rob Cutler and Thalia Vitikos, MA, LMHC

At the 2019 AutCom Conference, we were privileged to hear Rob Cutler and Thalia Vitikos present on their work together in therapy. Through their collaborative work, Rob was able to regain control of his life after spending years in an institution. Because of the interactive nature of the presentation, there is not a written transcript of Rob's part. With Rob's permission, his mother, Barbara Cutler, shared a history she wrote about Rob's PTSD (post-traumatic stress disorder). That handout follows this introduction. Thalia talked from notes but graciously wrote them into a form we can use in this newsletter to share this important information.

### Handout for Rob Cutler's Presentation on Life After PTSD at AutCom 2019

by Barbara Cutler  
 (Warning: Restraint and abuse are described in this article.)

*Between midnight and dawn when the past is all deception and the future futureless.* T.S. Eliot

It's been 36 years since Rob left Fernald (a state institution), but the vicious assaults he suffered there live on in his memory, nightmares and flashbacks. Rob was often restrained, so bruises were attributed to "behavior." Neither his seizures nor his atypical Parkinsonism were understood or even a matter of record. Every weekend Rob came home overnight, and we didn't see or hear anything significant. I visited Rob every weeknight and saw nothing, nor did any Fernald staff suggest Rob was being abused.

Move ahead four years to the morning Fernald called to report that they discovered at the morning change of staff that Rob had been beaten during the night. Two staff were on that shift: one a woman of average size, the other a heavy set, muscular, well over six-feet-tall man, Steven S. By the time I got to Fernald, Steven S was gone.

(Continued on page 4, column 1)

### Gaining Control of Your Life after PTSD

by Thalia Vitikos, MA, LMHC

First, I need to tell you that, as a therapist, I am grateful to Rob and his family for having been willing to work with me and teach me what I needed to know to work with people on the autism spectrum. The therapeutic process has been a collaboration built on mutual respect. Barbara, Rob's mother, and Rob taught me about autism, and I brought my knowledge and expertise working with people with PTSD. With their help, I have been in the position to help many others on the spectrum struggling with PTSD.

Second, as a clinician, I always do an Intake with a new referral. Because I do an Initial evaluation, it doesn't mean I am fully informed about the person's individual and family history, their identified traumas, symptoms, etc. My client's narrative or personal story unfolds gradually for a number of reasons.

Often people who have been traumatized need to avoid or don't have access to, or deny, or repress the painful memories. They need to find safety, a safe place from these memories. In so doing, they might label that time in their life as "bad." Often the traumatized person runs the risk

(Continued on page 4, middle of column 2)

(Rob's presentation continued)

Rob had two black eyes, and his mouth was swollen. He looked beaten in spirit as well as body. The woman who worked the 11-7 shift told the investigators that Rob was screaming "Call the police." She could not stand the screaming, so she went downstairs to do the laundry.

As far as the agency was concerned, there was only one beating, but one day a staff (Desmond) stopped me to say it was a blessing Rob's face had been battered or the almost nightly beatings would have gone on forever. Steven S avoided marking Rob's face to avoid discovery until this one night. Fernald never addressed the multiple beatings, and Desmond was not available to tell anyone, thus maintaining the institutional code of silence in which staff protected staff.

Fernald did not press charges. Administration said that he had quit. At the Waltham Courthouse, the DA was reluctant to show the pictures of Rob's swollen face, but I had already seen my battered son. At the "Show cause" hearing, the woman testified she left the floor to block out Rob's screams for help. I left to tell Rob that Steven S could no longer hurt him, that he was never coming back. Rob started to laugh hysterically, suddenly stopped, asked, "Never?" and, reassured, started to laugh wildly with relief. I once asked Rob where he had been hit, meaning on his body. He answered, "In my room," and shut down.

One Sunday morning we found Rob asleep with some vomit on his pajamas. Apparently, he had gotten up in the dark, threw up in the toilet, and went back to bed without calling for help. Don't make any noise. Get back to bed as fast and quietly as you can. And hope you are safe in a place where people are supposed to take care of you and when you scream for help, no one comes.

During one of Rob's flashbacks, he yelled, "You hit me. Now I have to kick you." If you understand the communicative form of echolalia you know that this is what Steven S said and did. Rob, 5'7" inches tall, was punched and kicked by S at 6'4", and there was no one to protect Rob. Steven S got a year's probation for violating someone in his care.

Years later, after Rob acquired facilitated communication, he told me the man had beaten him and gave an exact number – 394 times – in less than 4 years, 394 times. If you know autism, you know that is most likely a true figure. Rob also told us he was beaten all night and that he thought we knew and approved the beatings because he was autistic.

Over time, the flashbacks/meltdowns continued but seemed to be lessening until we were in a car accident and thus learned about "triggers." Rob had considerable pain, and that reinforced the Fernald nightmares. We worked hard to support Rob and help him feel safe. He told us the nightmares were worse than the flashbacks. With the flashbacks, we could try to pull him back and make him feel safe. In the nightmares, there was no one to help or care.

At the very least, returning war veterans suffering from PTSD knew their "brothers in arms" had their backs and that their "tours of duty" were limited, so they were never in the line of fire for extended periods of time. Rob had neither. For all he knew, he had "a life-long sentence with no one to come to his rescue."

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(Thalia's presentation continued)

of "throwing the baby out with the bathwater." This tendency to generalize or engage in "black and white thinking" can be a symptom of PTSD. For example, the child who was bullied decides that "my childhood was bad." This person loses any thread or connection to positive events, especially relationships that may have occurred alongside the "bad."

Third, as a therapist I need to recognize that it's not just my client who has been traumatized. It's the whole family. It is the mother who was forced to put her beloved son into a state institution in order to keep herself safe. It's the family who discovers their loved one has suffered chronic physical, verbal, emotional, and psychological abuse. The family is traumatized.

Fourth, people often ask, "In therapy, does a client need to go into their trauma in order to recover or may they stay away from painful memories?" In

general, what I have learned is that if the client isn't able or ready to confront the trauma, I will be met with what we call "client resistance," which is healthy. I won't be allowed to bring them to a place that is unsafe, nor should I. As a therapist, I listen, watch, and respect this response. I also remain fluid, knowing that over time, we may step a bit into the past, move to the present, and push forward into the future. My client directs this. For example, I currently have a client, older than Rob, who quickly changes the subject if we touch on any subject that triggers memories of Fernald.

And fifth, I do not believe that PTSD is always cured, certainly not when it's chronic because there are repeated instances of abuse. Complicated PTSD—man's inhumanity to man—is very difficult to work with as opposed to natural disasters.

### Treatment

Clearly, the client needs to develop effective coping skills on a number of levels.

1. The client needs to identify and integrate positive qualities and characteristics. These may be new or may be qualities the client once felt he possessed but lost due to trauma. For example, a person may identify as a victim. With some cognitive therapy, they may later identify as a survivor, also "kind and good man."
2. The client needs to develop boundaries, all kinds of boundaries. He needs to know and believe that the past stays in the past. This is why PTSD is so insidious. When we are triggered by something, the past rushes in, and we experience a flashback or intrinsic memory, symptoms of PTSD. The client needs to experience as much safety as possible.
3. The client needs to identify, and, if possible, avoid triggers or to develop interventions that decrease the intensity of the trigger (e.g., red brick buildings, rushing). Often this means putting supports in place.
4. The client needs to rebuild trust, because often it has been violated, or is perceived to have been violated. In Rob's case, the De-

partment of Mental Retardation (as it was called at the time) put him in this institution. His family agreed. Barbara later discovered that Rob's perception and interpretation of his institutionalization was that he was being punished for having autism. Trust needs to either be built or rebuilt. Also, the family needs to rebuild trust with the state system.

5. Cognitive behavior strategies include a relaxation/safety protocol and good communication with staff to avoid triggers.

### Rob's Treatment

1. Identifying and integrating positive qualities and characteristics, a cognitive therapy.
  - a. Rob always had movement difficulties. Between the ages of 18-20, Rob developed atypical Parkinsonism. He would become stuck in a movement loop and lost control of his body, not being able to move at all. Rob discovered that the only way he could move was to become enraged. The rage seemed to distract him enough so that he could move. At this time, Rob's and his family's situation became very difficult.
 

Initially Rob seemed to identify with being a bad person. He didn't directly say or type this, but he repeatedly typed, "I am a good man." He did this so frequently that it sounded like the defense mechanism we call "reaction formation." Over time, I think that Rob started to believe this truth. Now, he types and speaks it less. I believe that he has internalized it.
  - b. Over time, I observed that Rob is a very kind, compassionate and empathetic human being. More recently, Barbara has shared how Rob showed an abundance of empathy and compassion as a young child, especially with his father who left when Rob was four. It seems to me we have been able to talk more about the past. Again, the "baby may have been thrown out with the bathwaters" when we consider what occurred when Rob got older.
  - c. Barbara disclosed to me that Rob believed (Thalia's Presentation continued on next page)

(Thalia's Presentation continued)

that he was being beaten at the institution because he had autism and he was "behaviorally disordered." What was worse was that Rob had come to believe that his mother agreed with this. Rob now knows this is not true. He no longer identifies as a bad person who deserves to be abused. He now knows that he has neurosensory and motor difficulties that no one blames him for.

d. Rob now feels that he is a survivor and not a victim.

## 2. Establishing boundaries – places that feel safe

Rob has learned to feel safe in many places – his home and his mother's home; at lunch with Bonnie; with Michael doing work for Medicine Wheel, which gives Rob a profound sense

of purpose; at Wild Acres; with his brother George and his family.

## 3. Identification of triggers

- As stated, being rushed is a trigger
- Unreliable staff with whom Rob doesn't feel safe. What happens if he can't be kept safe? Staff not implementing safety strategies
- Being unable to communicate
- Not enough time to rest and experience sensory integration
- Physical, chronic pain

## 4. Ways to feel grounded: walks, weighted blanket, being in nature, music

## What Works to Support People Who Have Severe Challenging Behaviors

by Nancy Weiss, Director, National Leadership Consortium on Developmental Disabilities, University of Delaware, 2019

We often work with disability service agencies to assist them in their shift from offering congregate services in group homes, center-based day programs and the like, to instead offering personalized supports that assist each person to live a good, full, self-directed life. People sometimes ask whether this individualized support model works for people with disabilities who have dangerous or self-destructive behaviors. When we offer rich, satisfying lives, when people with disabilities are in charge of their own lives, when people's wants and needs are heard and we respond to them, when we are not restricting, isolating and controlling people, much of the challenging behavior we see in structured, segregated settings just fades away. Behaviors that challenge us and the people who experience them are often motivated by restrictive settings and therefore, they recede when those behaviors are no longer needed.

Staff members of agencies that support people with disabilities, often ask questions along the lines of "What should we do with people who have behavior problems?" Questions like this imply that people's behaviors are an indication of intrinsic

deficits – problems within people that need to be fixed. When asked how to best support people whose behaviors present challenges I often ask for an example. "Well," explained one woman recently, "there's this guy -- he can get violent. He'll hit or kick for no reason. We have a hard time finding staff who will work with him. We don't pay people enough to want to work with a person like him." I asked her to tell me about this man and when he might hit or kick. "Any time – completely unprovoked – he'll just go off". When I asked her to describe the most recent time he hit or kicked someone she said, "Just the other day -- staff went into his room to wake him up – he's hard to get up. He never gets going on time. Staff don't yell at him or anything – they just say, just like to everyone else, 'Gary, time to get up'. And then all morning he's dragging around and resistant – we have to prod him – 'time to brush your teeth', 'you need to get into the shower'...we tell him he's going to hold up the whole group, the van is going to be here any minute, we're going to be late for day program. He's always the last person to eat breakfast – and then at any point, he might lash

out and hit or kick.

You don't have to have any particular behavioral expertise to analyze this story. Somehow however, this apparently well-meaning person had convinced herself that it was Gary who was the problem rather than the frustration of living a life in which he was constantly told what to do and in which he was expected to do what works for the staff, the agency and the schedule rather than what works for him. The person who spoke with me felt that she was asking a perfectly reasonable question about how to handle people who are problematic. She didn't see that she was telling a story about a person's perfectly understandable response to a dismal 'we're-in-charge-and-you're-not' situation that service systems so often impose.

People will tell me that some of the people with disabilities they support are 'noncompliant'. When did compliance become a personality characteristic to which we aspire? None of my women friends have ever said, "I went out on a date the other night. I really like this guy – he's nice, good-looking and he seemed so compliant!" I've never told my friends about my daughter's accomplishments by bragging about how compliant she is. Compliance is only celebrated in people who we, at some gut level, feel are not our equals or who we feel should act in ways that justify the way we treat them. If they make our lives difficult through their behaviors, shouldn't we be able to retaliate just a bit by making their lives less pleasant in return?

I am not a person who thinks that because all people are to be valued and respected, that all behavior is OK. Anyone who has worked in the real world knows that there are people whose behaviors are self-destructive, dangerous or disruptive to the point of interfering in their opportunities for happy, connected, self-directed lives. We owe it to people to help them regain control so they can lead good lives. We don't owe it to people to control, restrict or isolate them – even if we've convinced ourselves it's for their own good.

I've been asked for help to address all kinds of behaviors that people who work in this field find problematic. One staff team requested help to change the behavior of a woman who came home from her life-dulling day program and cut up magazines for an hour or so, keeping her snipped

paper in shoe boxes under her bed. "It sounds like she enjoys it, it's probably comforting", I offered. The staff were determined to convince me that her behavior was a problem. I asked if she might be bored. What else did she like doing? What other kinds of past-times had they supported her to explore? What were her other options for things to do? I recommended that they try to figure out what other things she might enjoy, but if she liked snipping paper, I suggested they not worry about it. "But it's not normal", a staff member insisted. The real answer is to assure that every person who receives support has a rich, interesting life .... then, if snipping magazines and storing confetti still feels soothing or fun, we should assure a supply of magazines and shoe boxes.

With input from some people who have been victim to our, at-best clumsy and controlling, and sometimes downright cruel and manipulative attempts at behavior change, I have put together some suggestions for people who work with people with disabilities. This article discusses better ways to think about behaviors that challenge us and to support people who have these behaviors.

Make sure the person is able to communicate their preferences and that we are listening and responding. 'What about people who don't communicate?' I am often asked. Everyone communicates – but not always with words and not always in ways that are easy to interpret. People who know people with disabilities well know what pleases them and what annoys them. It's our job to try to build a full understanding of what works (and doesn't work) for each person we support. At an early morning visit to a group home, one woman was stomping about – clearly peeved. "Don't mind her", the staff person explained. She hates eggs and she gets into a huff whenever we have them for breakfast." I asked whether she couldn't have something else. The staff person said she guessed so, but her tone conveyed that this would present an inconvenience. "The thing is," she said, "If we give her what she wants, all four of them would want something different." This staff person had correctly interpreted the reason for the woman's behavior (annoyed at being forced to follow a menu that didn't appeal), she

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(What Works continued)

unfortunately had just decided that going along with what was planned was more important than responding to personal preferences. Not only was this woman given a meal she didn't prefer, she got served something else as well; another example of something she'd likely been forced to face over-and-over in her life -- that her preferences didn't matter and her efforts to make her choices known would be ignored in service of expediency.

If people can't (or don't) communicate with words, it is incumbent upon us to try all possible ways to identify a communication method that works for them so they are able to get their feelings and desires across. People who can communicate effectively using any method have less of a need to communicate through their behavior. Once we know what people are conveying through their behavior, it's our job to make the changes in the environment, schedule, or available options to respond to their communication. This kind of personalized responsiveness is much more likely to happen when each person's supports are tailored to them, rather than when they are expected to fit into the more structured service models we've constructed.

Make sure the person's behavior isn't a response to a medical or psychiatric issue. When people's behaviors challenge us they are likely either protesting against the limiting and restrictive lives we offer or telling us that they are in physical or psychological pain. There have been hundreds of instances in which people have been punished, had treasured belongings taken away, were made to earn things that they like or want, or had rights restricted because people were responding to pain, discomfort or confusion and were trying to convey this in the only way available to them. Prior to addressing any behavioral issue, we need to assess any possible physical or emotional pain and assure that medical treatment or supports that may be helpful such as counseling, a change of environment or demands, or psychoactive medications for depression, bipolar disorder, schizophrenia and the like, are offered.

Assure that people have choice and control. We often have offered people services that work for the agencies and staff that serve them or that

achieve goals that others think are right for them, but that are not what people want. There is a need to check our assumptions that we know what is best for people and re-think the other-centric service approaches that have become second nature. Instead, we need to figure out all the ways to offer lives, environments and supports that honor each person's needs and preferences. We have slots, openings or beds that may not be what a person would choose but that we need to fill to make the financial side of services work. We design systems that we think will work for all but are unlikely to work for each. Some people need solitude and quiet, some want social, engaged lives. Everyone needs to feel safe and everyone wants people in their lives who love and support them.

Being the lifelong target of care-taking can be oppressive. We are sometimes benevolent to the point of malevolence. Our 'being there' for the people we support has created a barrier to their being a part of their communities and to their building real and sustaining friendships. Paid relationships are almost always time-limited and this kind of relationship can't hold a candle to friendships that form naturally out of shared interests or compatible personalities. All people should live the life they choose, design and control with the supports they need for success – and when they do, they'll have less of a need to behave in ways that are challenging.

Figure out what behaviors achieve for the person. People act as they do in an effort to communicate and because their actions fulfill a need or function for them. Sometimes the functions that a behavior achieves for a person are not obvious or straightforward. Figuring out the purposes that a behavior achieves takes conversations with the person when possible, discussions with people who know and love the person, and often, considerable observation and conjecture. Sometimes the behavior achieved something for the person in the past and, while it no longer achieves that purpose, the behavior has been learned or has become habit. Understanding that a behavior can be learned is good news; one reasonably then must assume that behaviors can be unlearned once they cease to achieve a function for the person. Sometimes behaviors



are simply comforting in a world that has stripped people of comfort, control and safety. People may need to learn other ways to attain anything that self-destructive or dangerous behaviors had been achieving for them. Once the purposes or functions of the behavior are revealed, the challenge is to assure that whatever was being sought through those behaviors is made plentiful in the person's life. We tend to do the opposite – we think, 'He is doing that just to get attention. We can't let him manipulate the situation!' Our thinking needs to change. We must assure people that they do have power; that they are in charge. Whatever the behavior sought to achieve needs to be freely available or easily attained so people have their needs met without having to act in dangerous or dramatic ways to achieve comfort, control and a good life.

Support people who are in the midst of a dangerous or severely disruptive behavior to be safe, while helping them find their way back to regain internal control. The way to help people regain control is different for every person. The goal is to help people find tools that they can learn and use, call upon, keep, and make a part of themselves. These might include listening to favorite music; holding a comforting object; going for a walk, a run or playing basketball; talking with a friend; spending quiet time in a calm space alone or with a pet – the tools for each person will need to be discovered through conversation, observation and trying out a variety of things. It is sometimes necessary to prevent people from hurting themselves or someone else but the worst way to help someone feel safe or to regain control is to yell, instruct, restrain, argue, limit, berate or punish them. It is just common sense that these approaches will only exacerbate a person's feelings of being out-of-control and less worthy. It is not only cruel and unethical but downright illogical to respond to people's attempts to assert a degree of control over their lives by imposing greater and greater amounts of power over them -- but this is exactly what is often done with little consideration of logic or fairness.

Understand that offering "choices" can be a way to further assert control. Michael Kennedy, a leader with the Self Advocacy Association of

New York State once said that whenever he hears an agency staff person say that they 'give people choices', he knows something is wrong. Choice isn't something to be doled out as one would a treat. It is not something that should have to be earned. The right to choose should be assumed – not something that is granted or withheld. Staff often offer choices that are so narrowly constrained (do you want peas or broccoli?) or so limited (do you want to go to a movie or to the mall?) that they are not real choices at all. Real choice involves familiarizing people with the whole range of possibilities, letting them experiment, and supporting them to discover their preferences, interests and passions.

Recognize that behavior often grows out of a history of trauma. It is the rare person who has severe difficult behaviors and who has not had a traumatic life. The statistics on people with disabilities who have been physically and/or sexually abused are horrifying – and even those people who have not experienced particular traumatic events have likely lived lives characterized by way too much external control. They likely have experienced being demeaned, rejected or excluded. It is theorized that living a life that is never your own, being expected to act as you are instructed, and having few opportunities for self-agency is as likely to result in post traumatic stress disorder as does experiencing specific traumatic events. Herb Lovett in his seminal book, *Learning to Listen*, noted, "People who have been hurt in the name of therapy may not understand their plight any differently than survivors of cult abuse or sexual abuse.... every time they recall their previous maltreatment, unless their panic and rage are recognized as a function of stress, they are likely to be further stigmatized as 'impossible to serve' ". (1) All interactions with people who have led lives of trauma and control need to be rooted in understanding their history and serve to acknowledge and heal past hurts.

The critical component of supporting people who have been victims of every day or periodic trauma is providing life environments in which people feel fully safe, have trust and are trusted, and have a range of relationships with people

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(What Works continued)

they love and care for and who love and care for them. Such environments are characterized by acceptance, consistency, reliability, predictability, availability, honesty and transparency. (2)

Some behaviors are difficult for both people who care for/care about people with disabilities and the people themselves who have those behaviors. Some of these difficult behaviors are learned in response to a service system that strips people with disabilities of their power. There is literally no greater human impulse than for each of us to be in charge of our own life. We put people in situations that strip them of control, safety and choice and then wonder why they 'act out' in protest.

The most important changes we need to make to do a good job of supporting people who have

behaviors that are challenging, usually have little to do with changing the person. Changes need to focus on situations and supports so that they offer opportunities for life-affirming, engaged, fulfilling lives; lives that don't call for protest. Once choice and control sit firmly where they rightly should, the need to behave in ways that serve to push back against people trying to assert control or that attempt to resist the limiting lives that are offered, naturally resolves.

1. Lovett, H. (1996). *Learning to listen: Positive approaches and people with difficult behavior*. Brookes Publishing: Baltimore, p. 208

2. Bath, H. (2008). *The three pillars of trauma-informed care, Reclaiming Children and Youth*. Vol. 17, no. 3, p. 17-21

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## What Your Child on the Spectrum Really Needs: Advice from 12 Autistic Adults

by Jenna Gensic, Autism Asperger Publishing, 2020

Review by Anne Carpenter

I wasn't sure what to expect when I started to read this book, but I had a feeling that it would be a cut above other parenting books that focus mostly on what parents and teachers have to say, often leaving out autism voices. I was duly rewarded, but also surprised at the roster of adults. These were not the usual people. Temple Grandin is nowhere to be found. While there are references to quotations by Stephen Shore, he is not featured, either. Rather, we have Lydia X. Z. Brown, an Asian woman who is an Autistic activist, writer and speaker, focusing on violence against people with disabilities who are multiply marginalized; Gavin Bollard, an Australian information technology specialist and autism blogger with two sons who are also on the autism spectrum; Amy Gravino, a certified college coach, who also runs a private consulting firm, Asperger Syndrome Coaching and Other Techniques (ASCOT); Brian King, a cancer survivor and author, a Life Coach who has spoken extensively on communication and collaboration; and many others who are powerful in their insights.

Beginning with Brown, Chapter 1 focuses on not to try to fix one's child, but rather to accept and embrace her or him as is. Brown decries the

use of "high-functioning" and "low-functioning," as these labels create an uneven playing field resulting in stereotypes. She also questions the romanticized notion of "Asperger syndrome" as being "better" than autism and notes that it may be more disabling in some ways because of the more pronounced difficulties with socialization.

Following on the heels of that is the subject of social integration and the tricky problem of hiding one's autism, or "camouflaging," to look more like the so-called "neurotypical" people, which often causes a great deal of stress and sometimes even results in serious mental health issues. Other topics included creating a safe environment, the use of social manuals to help with social skills, and meditation as a way to reduce stress by Tim Page, motor planning and sensory processing challenges with Jodie Van Der Wetering, a stand-up comedian from Australia, adolescence and sexuality, as discussed with Amy Gravino, successful employment with Gavin Bollard, and more.

Each chapter provides rich insights from the respective individual and includes a set of Reflection Questions at the end, so that one can really think about the material and incorporate

the concepts in one's mind. In addition, there is a section of advice for parents and one for autistic individuals. The book reflects the newer, more positive view of autism as put forward by the neurodiversity movement, which views autism not as a disease, but as a variation in overall

neurological functioning. While autism does impose difficulties, I would hope that we can err on the side of neurodiversity. This book is a step in the right direction.

This review first appeared in a publication by Autism Society of Michigan.

## AutCom Protests FDA Ruling on Shock Treatment

To: Dr. Stephen M. Hahn, M.D. – Commissioner, U.S. Food and Drug Administration  
10902 New Hampshire Avenue, Silver Spring, MD 20993 [stephen.hahn@fda.hhs.gov](mailto:stephen.hahn@fda.hhs.gov)

April 9, 2020

Dear Dr. Hahn,

I am writing as President of AutCom to express very deep concern and outrage that there will be a delay in implementing the March ruling by the FDA to ban the use of electric skin shock devices. People subjected to these appalling devices experience physical and emotional pain with each and every day that passes during any delay in implementing this much-needed ban.

In January of this year, the FDA ruled to ban electrical skin shock devices for self-injurious or aggressive behavior. As expected, the Judge Rotenberg Center (JRC), the only site where these devices are used, has appealed that decision, and the FDA has granted that appeal in part. JRC requested the petition for stay of action, arguing that the Judge Rotenberg Center and its patients will suffer irreparable injury if they are not allowed to use the electric skin shock devices. They also justified their request as necessary "in light of the recent presidential declaration of a national emergency concerning COVID-19".

The FDA responded by stating that they find that it IS in the public interest and the interest of justice to grant a stay (or a delay of the ban) in part. We strongly disagree. They are delaying enforcement of the ban on the use of these devices for the duration of the public health emergency related to COVID-19. Once the public health emergency ends, the stay (delay) will continue in effect until 1) the FDA substantively responds to JRC's petition; and 2) if the FDA does not grant their petition, JRC has adequate time and reasonable opportunity to obtain a ruling from the DC Circuit Court regarding a stay of the FDA's ruling. The stay (or delay of enforcement) is limited to those devices that

are currently used on people who would need a physician-directed transition plan in order to cease use of the devices. The effective date for all other devices (presumably, any in use on people who don't require a physician-directed transition plan) remains as April 6, 2020.

AutCom was founded 30 years ago, in part, to end such abuses as the use of electric skin shock and other painful and harmful restrictive approaches like the ones seen at JRC. Not only are they dangerous and inhumane, they are wholly imprudent in their intent. Self-injurious and aggressive behaviors are a form of communication. Suppressing those outlets without first determining and addressing their causes benefits no one. The medical and social services communities need to listen to the survivors of these abuses, who may choose to communicate in many ways besides or in addition to speech, and then reflect on their own contributions to the problems brought on by own failure to discover and remediate the actual causes of the behaviors.

We at AutCom are strongly opposed to the JRC's appeal and any delay in ending the inhumane, painful, and psychologically damaging use of aversive electric skin shock. The individuals affected are disenfranchised, many of them autistic, and many have no voice to protest. One of AutCom's founding members, Barbara Cutler, reminds us that the JRC has a long history of horror and death on its hands. It must stop NOW.

Lisa A. Keller, MS, CCC/SLP, AAC Specialist  
President, AutCom (Autism National Committee)  
Owner, Supported Communication Services, LLC  
[supportedcommunication.com](http://supportedcommunication.com)

## Online Informational, Educational, and Recreational Resources (FREE)

### Thoughts on education at home and quarantine schooling

On Quarantine Schooling by Be a Teaching Unicorn blog

<https://teachingunicorn.com/2020/03/30/on-quarantine-school/>

Edutopia: Why learning at home should be more self directed and less structured

<https://www.edutopia.org/article/why-learning-home-should-more-self-directed-and-less-structured>

### Education at home and quarantine schooling resources

Living and Learning at Home During a Pandemic!  
By Autism Level Up - Amy C. Laurent, PhD,  
OTR/L and JÂcquelyn Fede, PhD. Downloadable  
and sharable file:

[https://drive.google.com/file/d/1rJZGg0\\_ZZq2GUR6bQtugC3nHKNzoK5Y4/view?usp=sharing](https://drive.google.com/file/d/1rJZGg0_ZZq2GUR6bQtugC3nHKNzoK5Y4/view?usp=sharing)

Amy Laurent - Supports and Resources Archives  
- Supporting children, parents, and educators

<http://amy-laurent.com/category/supports-resources/>

At-Home Resources for Families – chart with  
embedded links

[https://docs.google.com/document/d/1pnYG6VX\\_Ao60pLSX5SQvCnVRUHvDJfiGU8tc3t-ZUepo/mobilebasic?usp=gmail\\_thread](https://docs.google.com/document/d/1pnYG6VX_Ao60pLSX5SQvCnVRUHvDJfiGU8tc3t-ZUepo/mobilebasic?usp=gmail_thread)

Homeschool/virtual learning tips by Paula Kluth  
on Facebook

<https://www.facebook.com/paulakluth>

### Virtual tours and more

Google Arts and Culture site: famous structures,  
museums and other locations all over the world;  
entertainment and educational sites, tours, and  
options.

<https://artsandculture.google.com/>

Virtual Tour Mount Vernon

<https://virtualtour.mountvernon.org/>

Virtual Tour Yosemite National Park

<https://virtualyosemite.org/virtual-tour/>

NASA High Definition Video Gallery  
<https://www.nasa.gov/content/ultra-high-definition-video-gallery>

gives access to Nasa's collection of amazingly  
detailed views of the earth, the moon, other  
planets, and deep space.



### My Outrage

By Yasmin Arshad

When I was dearly wishing it  
My family told me I'd never drive.  
When I was sadly missing it  
My mother told me I'd never parent.  
When I was really feeling it  
My father called me dumb.  
When I really gave my love  
My teachers only got me mad.  
People have never understood  
The special feelings I may have.  
Only believe in me  
And I will grow up too!

## COVID-19 Resources

CommunicationFIRST has prepared a COVID-19 Communication Rights Toolkit

<https://communicationfirst.org/covid-19-communication-rights-blog/>

Access the COVID-19 Communication Rights Toolkit here:

<https://communicationfirst.org/covid-19/>

US Department of Education - Questions and Answers on Providing Services to Children with Disabilities During The Coronavirus Disease 2019 Outbreak - March 2020

<https://www2.ed.gov/policy/speced/guid/idea/memosdcltrs/qa-covid-19-03-12-2020.pdf>

HHS Warns States Not To Put People With Disabilities At The Back Of The Line For Care. March 28, 2020 7:23 PM ET

<https://www.npr.org/2020/03/28/823254597/hhs-warns-states-not-to-put-people-with-disabilities-at-the-back-of-the-line-for>

OCR Issues Bulletin on Civil Rights Laws and HIPAA Flexibilities That Apply During the COVID-19 Emergency. "The Office for Civil Rights enforces Section 1557 of the Affordable Care Act and Section 504 of the Rehabilitation Act which prohibit discrimination on the basis of disability in HHS funded health programs or activities. These laws, like other civil rights statutes OCR enforces, remain in effect. As such, persons with disabilities should not be denied medical care on the basis of stereotypes, assessments of quality of life, or judgments about a person's relative "worth" based on the presence or absence of disabilities."

<https://www.hhs.gov/about/news/2020/03/28/ocr-issues-bulletin-on-civil-rights-laws-and-hipaa-flexibilities-that-apply-during-the-covid-19-emergency.html>

Bulletin: Civil Rights, HIPAA, and the Coronavirus Disease 2019 (COVID-19), Office of Civil Rights, US Dept. of Health and Human Services, March 28, 2020.

[www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf](http://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf)



## In Memoriam

### Mel Baggs 1980 – 2020

It was with a sense of great loss that we heard the sad news that autistic advocate Mel Baggs has died. Mel's life, leadership, and advocacy for autistic rights, respect, justice, acceptance, understanding, and access to communication have changed many lives for the better. Mel's powerful presence and influence will be greatly missed.

Mel Baggs, formerly known as Amanda Baggs, was a writer and self-videographer who derided the way autism is portrayed by much of the non-autistic world. Mel's preferred pronouns are sie and hir (which are used in this tribute).

Mel communicated by typing. As sie reported on The Art of Autism Blog, "I slowly lost both speech-in-general and speech-as-communication starting in adolescence and continuing into early adulthood. I use both typing and picture symbols depending on what I need at the time." <https://the-art-of-autism.com/r-i-p-non-speaking-advocate-mel-baggs/>

Mel spent many years in an institution before returning to community to live in hir own place with help as needed by long-time friend Laura Tisoncik. Sie lived with Laura for the last year of hir life.

AutCom discovered Mel when sie created "In My Language" in 2007 and posted it on youtube – <https://youtu.be/JnylM1hl2jc> (8:36; captioned). It is a "statement about what gets considered thought, intelligence, personhood, language, and communication, and what does not." Mel presented at four AutCom conferences over the next few years.

(Continued on next page)

(Mel Baggs continued)

In response to the Autism Speaks campaign, "Getting the Word Out," Mel developed "Getting the Truth Out." <https://web.archive.org/web/20060202212252/http://gettingthetruthout.org/>

Mel blogged on <https://cussinanddiscussin.wordpress.com/>. His last post was on April 10. She died the next day.

Mel's stature as a leader in the disability rights

movement has been recognized in extensive obituary articles in the New York Times and The Washington Post as well as in both of his local papers. She will live on in his important body of work which resists medical, psychological, and popular misunderstanding of autism. For a poignant tribute, visit the site of one of his many fans, Michael John Carley: <http://www.michaeljohncarley.com/index.php/rip-mel-baggs.html>. On Carley's site, be sure to watch Mel's video, "Happy Dance."

## ***Fall Down 7 Times, Get Up 8: A Young Man's Voice from the Silence of Autism***

by Naoki Higashida, Random House, 2017

Review by Anne Carpenter -This review first appeared in a publication by Autism Society of Michigan.

Among all the books written by people with autism, people who are more severely affected, with more difficulty with communication, movement and emotional regulation and sensory processing, are often lost in the shuffle and as a result, those most impacted by autism are not as well understood. Naoki Higashida shone a brighter light on this with his bestselling book *The Reason I Jump*, in which he wrote about his experience with autism as a young boy.

Now, as a young man in his twenties, he has written another gem, *Fall Down 7 Times, Get Up 8*. It continues where he left off, but he must now contend with the frustrations that adulthood brings, such as continuing to need support and help with everyday functioning, including communicating wants and needs. Using a letter grid that was improvised by his mother, he communicates through a laborious process of selecting the letters one by one, often distracted by other things going on around him. Although to an observer he may appear to not understand what is going on, his writing reveals a treasure-trove of impressions and thoughts, such as why he lets the bath water get cold, even when it is cold outside, and his frustration at an umbrella that wouldn't close shut. Only when his mother showed him the corroded, rusty fastener was he able to accept that he

couldn't close that umbrella.

This book is divided into sections, "The View From Here," "Speech Bubbles," "School Years," "Inner Weather," "Handle With Care," with each chapter focusing on a specific aspect of his life and how he does everything he can to work around the many challenges he faces each day. He continues to grow, change and learn, but still must contend with distractions, meltdowns, obsessions and continuing difficulties with communication. His alphabet grid allows him to open the door for others to view a mind that often processes the world more intensely than others and that necessitates more effort in doing what we take for granted everyday, such as getting dressed, bathing, eating meals and getting around town. He doesn't have a job or a girlfriend and continues to need support, so he lives with his parents in Japan. His family is a very loving one, and that can make a world of difference!

I just loved this book to pieces; it was beautifully written, yet easy to understand and to help the reader know what hoops the author has to jump through, just to get through another day. One can feel his anger, frustration and, also, compassion and hope in the face of great odds. Another person could crumble under this great weight, but Naoki Higashida has resolved to stand tall.

## Thumbs Up and Thumbs Down

### Thumbs Up

US Department of Education guidance on IDEA and IEPs during the coronavirus disease outbreak. Excerpt: "If an LEA continues to provide educational opportunities to the general student population during a school closure, the school must ensure that students with disabilities also have equal access to the same opportunities, including the provision of FAPE." (See COVID-19 Resources for link.)

US Department of Education's new efforts to combat the use of restraint and seclusion (captioned webinar)

<https://www.youtube.com/watch?v=EZ9Yx0LC8Tl&fbclid=IwAR3mpm9RTVyglwzWjSX9AH0YUYd-j3y9ORRo5RSwwjaOFYvJFAHW0YwApUI>

US Department of Health and Human Services and Office of Civil Rights advising states and hospitals not to discriminate in provision of health care services. (See COVID-19 Resources for more link.)

FDA ban on the use of electric skin shock devices in March (following many years of hard work by disability advocates plus media attention), devices currently in use at the Judge Rotenberg Center in Massachusetts (see Thumbs Down for info on an April stay). FDA Takes Rare Step to Ban Electrical Stimulation Devices for Self-Injurious or Aggressive Behavior: Devices Found to Present Unreasonable and Substantial Risk of Illness or Injury

<https://www.fda.gov/news-events/press-announcements/fda-takes-rare-step-ban-electrical-stimulation-devices-self-injurious-or-aggressive-behavior>

Action by the Autistic Self Advocacy Network & its partners to challenge the State of Washington's discriminatory COVID-19 Plan, which could discriminate against and put at risk the lives of people with disabilities.

<https://autisticadvocacy.org/2020/03/asan-partners-challenge-wa-discriminatory-covid19-plan/>

Care and collaboration among states, hospitals, communities, and neighbors assisting each other during the current global COVID-19 health crisis and consequent quarantine schooling, including individuals taking reasonable, responsible personal precautions for the safety of themselves and thereby everyone else, too.

### Thumbs Down

Following the March 2020 FDA ban on the use of electric skin shock devices, Judge Rotenberg Center filed for and was granted in April 2020 an administrative partial stay of the ban, which it uses on its clients who have a history of aggressive or self-injurious behavior. The stay is to remain in effect during the health emergency associated with the COVID19 virus and until JRC has litigated in the courts all of its appeals against the ban.

<https://autistichoya.files.wordpress.com/2020/04/fda-notice-of-stay-filed-with-court-of-appeals.pdf>

## DJ Savarese's United Nations Talk

Hi, Everyone. My name is David James Savarese, and I'm honored to be here at the United Nations today as an OSF Human Rights Initiative Youth Fellow, an artful activist, and one of many alternatively communicating autistics, to talk to you about assistive technology and active participation. If asked, we would all agree that communication and freedom are basic human rights, but how we define these concepts can greatly affect who does and does not have access to them.

Each of us has the capacity to make the world a better place. Knowing and believing that is called "self-efficacy." People say too much time is spent listening to fear. They're right. Making yourself mad or afraid about something isn't what makes for change. Hope—not fear—is what drives our self-efficacy.

I leave viewers at the end of my documentary film, with the reminder that "Hope lives on—messy, imperfect." I say this because hope takes work. We need to nurture it by meaningfully engaging with others about what matters. Each success fosters our belief in ourselves. If I'm hopeful, I'm open to other ideas. I'm making a difference in others' lives, not just my own. It's my hope that all people will get the support they need to be able to actively participate, not just as individuals, but as a part of something greater than themselves.

I'm often asked how I've managed to thrive and to remain hopeful in a world in which many nonspeaking people are segregated all of their lives. People might say I'm thriving because of all I've accomplished, but I would say I'm thriving because I'm growing and connecting in a lot of different directions simultaneously, and I have been for the past twenty years. I would say I'm thriving because I live life rhizomatically. It's interdependence we're striving for here, the right to a rhizomatic way of life in the cultivated garden of a self-reliant, speech-based society.

But why rhizomes you ask? Well, unlike so-called "true roots," which have single roots and stems, rhizomes persevere by creating an intricate network of multiple root bulbs full of nutrients and resources that grow both vertically and laterally. If cut down, they grow back. Faced with adverse

conditions, they can lie dormant underground for up to a year, rejuvenating themselves before blossoming again. In this sense, weeding them out is far more difficult, if not impossible. With no center or defined boundaries, a rhizome is limited only by its environment, by where it lives.

My life has been a journey of opportunity. And I show some of that journey in my film *Deej: Inclusion Shouldn't Be a Lottery*, not to glorify myself, but to show the world what is possible, to disrupt misperceptions about us, and to paint a portrait of active participation and interdependence. It's my way of giving back for all the chances I've been given. I agreed to make the film, not to say I made a film or to best myself in film, but to free other nonspeaking people to build their own lives as they wish.

I used to think freedom was independence, and now I realize freedom is the room to breathe and to grow. Freedom is about connecting with others. Interdependence is hopeful and involves relating to ourselves as an integral part of something bigger than ourselves. Interdependence makes it possible for us to both get support and meaningfully engage with others. Interdependence follows the heart, not the head, and seeks connections, not divisions. Interdependence makes us feel safer in our own skin.

When people need us, we're assessed by them as gold. It's not easy being assisted by others and needing them in order to do our work, but when our work assists others to learn to read and write or to follow their dreams or to understand what they have been misperceiving all along, then we're able to work and to fearlessly hope for better lives for our people.

Assistive Technology has transformed autistics' ability to meaningfully and actively participate in the broader world. Not only has it brought us together as a political entity, it has also given a voice to the voiceless. Technology usually makes people think about computers and motorized apparatus. And certainly high tech advances have improved our lives. For example, the Autistic Self Advocacy Network (ASAN) uses the internet to leverage political power efficiently and effectively. Computers



and augmentative communication devices have also given alternative communicators a voice that is both easy for everyone to comprehend and efficient and sophisticated enough for us to convey complicated ideas in a timely manner. It allows us to shape the discussions we're having about our people, as well as the world around us. Computers and text-to-speech software give us a voice to be heard by large groups of people. And each exchange is mutually beneficial. No longer isolated and dependent upon others to advocate for us, we are empowered to make a difference and to represent ourselves. That is self-efficacy. That is freedom in my estimation.

Technology can also offer us alternative paths to literacy and a public presence in classes from the beginning. As early as kindergarten, a single switch Big Mac can be used to say "Here" each morning during attendance. Boardmaker can create the picture icons needed in early elementary school to create sentences, paragraphs, stories, reports and poems. Later, technology can help us become expected & valued participants in class discussions in Physical Science, AP English, or a First Year Seminar at College. Technology can assist us to present on the nervous system and our voluntary and involuntary movements in Anatomy and Physiology class, or create and co-direct a theatre performance. It can also help us keynote, present and advocate at conferences, universities, or on national television.

But it needn't always be high tech. When I was little, I used lots of food labels and photos to tell people what I wanted, to understand my choices, and to comprehend where I was going and what we were about to eat. In my case, I needed to be able to touch the words in order to master communication. If I'd been forced to use an iPad early on in my education, the lack of proprioceptive feedback and my motor precision would've tripped me up. Instead, using hard copies of the icons and words and velcroed answer banks allowed me to pick up the one I needed and place it in the spot where I wanted it to go. In this way, my teachers were able to see what I knew. A small device called a labeler that prints out words as stickers allowed me to make the transition from answer banks to writing on a computer or assistive device.

The website for my film describes me as someone "who uses a text-to-speech synthesizer to communicate." Yet, in truth, I, and so many of my peers, use a number of tools: augmentative communication devices, computers with text-to-speech software, our own vocal cords, written language, letterboards, emails, video-chats, g-chats, signs, gestures, objects, body movements, pointing, pictures, borrowing others' voices (by choice or by circumstance), even poetry and its oil paint animation (in the film).

We do not have a word for this kind of flexible communication. People like me are called "nonspeaking". Sometimes they add an adverb and say "minimally speaking." Uninformed people use the term "nonverbal." How can we be nonverbal when we use language every day?

When it comes to disability, we're stuck in a binomial universe of either/or, not both/and. I want a language of and, a radically interconnected one. What if we thought about communication strategies in this way? And, further, what if we thought about the need to create interdependent opportunities, opportunities that are somehow akin to the lateral network of root bulbs? We need multimodal communication to allow for maximum flexibility and accessibility.

If high tech options were my only means of communication, I wouldn't be where I am today. I use manual sign language to convey my essential commands: things like "I need to use the bathroom," "Please stop." "Go." "I'm done." "I need a break." "I need something to eat or to drink or more of something." I would never use my assistive technology to quickly tell someone I need to use the bathroom, but often people expect nonspeakers to use it first for mundane commands. I think it's not practical as the place to start.

We need communication to build relationships. It's those connections that make us thrive. It is this multimodal, rhizomatic approach to communicating—one that reaches out and up—that allows us to thrive and avoid isolation in a world that seeks to contain so-called nonspeaking people.

For us communication is only communication when it offers a web of support for ourselves and

(Continued on next page)

(DJ's UN Speech continued)

others. We want to grow that web to create a life of interdependence. We want to both learn and teach. We want to both support and be supported. If we're interdependent, we have satisfying relationships. We're neither alone nor are we strictly dependent on others. It's those relationships—not our ability to produce speech-like sounds—that offer us the safety we need to live.

It's important to remember that being nonspeaking does not mean we're nonverbal or unable to read and write. It just means that the complex, motor orchestration needed to utter words from our bodies takes longer to master. In the meantime, we have just as much right as anyone else—and perhaps a more urgent need—to learn to read and write.

The Convention on the Rights of Persons with Disabilities calls on every country to offer us the assistive technology needed to actively participate in every aspect of life: political, economic, educational, and social. It acknowledges that

assistive technology needn't be something fancy to work. It's these kinds of documents that are needed to ensure our human rights are preserved.

I challenge us all to leave this room today devoted to a new world. Maybe if we stop thinking of each other as able and disabled, verbal and nonverbal, speaking and nonspeaking, and instead, begin thinking of ourselves as a field of diverse and interconnected beings, life can begin anew for all of us.

I give thanks for our intricate and communal web of interdependence, self-efficacy, and perseverance.

May hope live on in all of us--- messily, imperfectly, and rhizomatically. Thank you.

David James "DJ" Savarese, WAAD, United Nations, NYC, April 2, 2019

Hear this speech and other wonderful panels of multimodal communicators and our fresh-thinking allies here: <https://www.youtube.com/watch?v=b7aYFQfoO0g>

## What is MNRI and why do we use it?

by Lisa Keller

Masgutova Neuromotor Reflex Integration (MNRI) is a technique that addresses and remediates primary reflexes that do not fully integrate, or that re-emerge in the event of trauma. (A reflex is a specific sensory stimulus that creates a specific motor response.)

Many of these reflexes are essential to survival, especially during periods of stress and danger. These reflexes are:

- Unconditioned responses that all babies are born with.
- At the foundation of development.
- Usually mature and integrate by the time the child is two years of age.

If the reflexes don't mature properly, the child may:

- form compensatory movements and behaviors that cost him/her time, energy and valuable resources.
- become "stuck" in these primary reflexes, causing his/her natural defenses to work against, instead of for him/her.

Unintegrated reflexes can cause inner chaos for the child who can't trust his/her body and natural defenses, and who can't predict how his/her body will react when faced with a stimulus. This causes many such children to shut down, become impulsive, or engage in aberrant behaviors.

Primary reflexes are typically checked at birth to ensure integrity of the neurological system; they are typically not rechecked again. During certain events that occur in utero, at birth, or later in life, a child or adult may experience trauma that affects the ability to use these reflex patterns effectively. In addition, stressful situations may cause an individual to revert to using early infant reflexes.

Primary reflexes, when not integrated, stimulate the fight or flight reaction, leaving the person at the mercy of his/her unreliable body. MNRI works to help integrate these reflexes by identifying and addressing them at a subcortical level, at the brainstem. The person learns to integrate the reflexes into more deliberate types of movements, bringing them under voluntary, cortical control.

This allows sensory information to travel from the brainstem to the top of the brain, where refinement happens at the cortex.

MNRI practitioners teach a sequence of re-education exercises and movements designed to further the training, maturation, and coordination of reflex patterns. The techniques are easily learned by parents, adults and professionals, and do not require many resources. MNRI practitioners have been instrumental in the recovery of trauma survivors, such as the children, parents, and other adults affected by the shootings at Sandy Hook Elementary school in Newtown, CT.

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[communicator@autcom.org](mailto:communicator@autcom.org)

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**Annual membership begins in January  
Membership form on next page**



### Principles of the Autism National Committee

As a member of the Autism National Committee, I endorse for all autistics and those with 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 communication 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.

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**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 print \_\_\_

I want to \_\_\_ Renew my membership \_\_\_ Become a member

I am a/an \_\_\_ Autistic person \_\_\_ Family member \_\_\_ Friend

\_\_\_ Student \_\_\_ Professional (field) \_\_\_\_\_

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 additional \$ \_\_\_\_\_ donation to speed up the good work!

As a donor, I want to be listed \_\_\_ by name \_\_\_ anonymously.

Send this form or a copy and a check payable to Autism National Committee to  
Anne Bakeman, AutCom Treasurer  
3 Bedford Green, South Burlington, VT 05403