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THE COMMUNICATOR

A Publication of the Autism National Committee

Welcome to our Fall issue, in which we continue the theme of self-determination, rights, and freedom. You will hear from autistics on the absolute and irrepressible need to be respected and treated as an adult, reflections on life as an autistic, gaining a voice and being heard in the world, navigating high school and college with accommodations, and daring to dream of what can and should be. Inside, there are also a thoughtful and in-depth review of "Deej" by an autistic, information on an alternative to guardianship, and news of a new organization promoting citizen directed supports. We invite you to read and share The Communicator far and wide.

We encourage you to join AutCom or renew your membership or even give someone a gift of membership to support our social justice mission. The modest membership fees pay for printing and distribution of this newsletter to promote the voices, dreams, and full participation and citizenship of autistics in the world.

Judy Bailey and Sandi McClennen – Co-Editors

Renew Your Membership!

Use the form on page 15
or
Go to the AutCom Web Site
www.autcom.org
Click on: Become a Member

Movement and Autism
by Lisa Keller
(A note from the new AutCom president)

Imagine, if you will, being locked in a really tiny room with many windows and vents. You can see everything happening outside the window. You can hear and smell everything. The people around you can move you and manipulate you. You cannot speak nor move purposefully. You are inundated by sounds and visions over which you have no control. People can touch you in ways that may not be welcome.

Frustrating? Frightening? Of course. And yet, inside your head you see wonderful colors. Lights and sounds mingle in ways that are soothing, even exciting. When you are given the opportunity to sit and be, you can indulge in the enjoyment of those senses, at peace with your body.

This is the way that autism has been described to me, a neurotypical. I can only guess at the sensations an autist experiences. The lucky ones—those with reliable speech, or who have learned to express themselves by typing—can describe it, but I will never grasp it firsthand.

As a Speech-Language Pathologist, I spent years trying to elicit spoken or gestural language from my students and clients. When AAC (Augmentative and Alternative Communication) was developed, everyone rejoiced that now the

(Continued on next page)

Inside This Issue:

(Movement and Autism cont.)

autist could make choices about his/her wants and needs. I felt smugly self-confident that this was all my students could ever want. After all, they were “intellectually delayed” and could have no expectations of a life beyond the here and now…right? They moved in funny ways and did strange things that no “normal” person would do. They were, according to the “experts,” less than a person. There was a spectrum, and the mistaken assumption associated with it at the time was that the more verbal you were, the “higher functioning” you were.

And then, in 1991, I found facilitated communication. Very long story short, I came to realize that movement—purposeful movement—was the missing component of communication. If you can’t move your body on command, nothing else is possible. The ability to think, look and move—in that very order—opens up a world that is otherwise denied the autistic person. The essential element for understanding autistic differences should be MOVEMENT, with sensory being a close second.

I believe in autistic people. I believe that they have intelligence and feelings and that they want what everyone else wants: a chance at a life with an education, a career, friends, and love. That is, in part, why I accepted the role of president of AutCom, provisional until we recruit a self-advocate to step in and provide strong, new, progressive leadership. I will always presume competence. I want to help those without a voice and those whose voices would be muted by nonbelievers. I ask that you join me. Your membership and donations will help us empower self-advocates as they strive to be heard. We are organizing the first conference in four years, to be held in 2019 in New Hampshire, and we are looking for autistic presenters and keynote speakers. Your participation is crucial.

Lisa Keller, MS, CCC/SLP
Supported Communication Services, LLC

I HAVE A DREAM

Victor Lam

I have a dream that people will think that we are all equal.

I have a dream that children will all go to the same schools whether they can talk or not.

I have a dream that all children will be taught and will learn.

I have a dream that important people will see that we are the smartest, not the dumbest.

I have a dream that just as blacks equal whites, we who cannot talk properly will be the equal of those who can.

I am a teenager with autism who doesn’t speak well. I have been treated as intellectually impaired because I couldn’t do IQ tests that require speech. In 2016 I started doing tests that don’t need speech and discovered I scored better than average. The problem is that I am in a school for children with intellectual disabilities, and they don’t teach us much.

I wrote my dream after watching Martin Luther King’s “I Have a Dream” speech.

Only by writing can I make you aware of what

I am thinking. Please do not judge us by what we say.

I want to go to university and learn how to write properly, so I can write philosophical stories to show the world that there is more to us than they realize, much more than we can say.

I am dreaming of a world in which our voices are heard by people everywhere, and in which all children will receive a proper education, regardless of whether they can speak.

My Life As A Girl With Autism

Tiffany Joy Broskoskie

I HAVE A VOICE AS LOUD AS A LION'S
ROAR IT IS DEEP DOWN IN ME LIKE A
BIRD AFRAID TO LEAVE ITS NEST FOR
THE FIRST TIME, NEITHER TIME OR LUCK
WILL WAKE THIS SLEEPING DRAGON,
BUT MY KNIGHT IN SHINING ARMOR
HAS ARRIVED TO RESCUE THIS PRINCESS
IN DISTRESS. RPM HAS AWAKENED MY VOICE
LIKE SLEEPING BEAUTY WAKING FROM HER
SLUMBER. ALL MY WORDS LEAVE MY BRAIN
LIKE A WATERFALL FLOWING INTO MY FINGER
ONTO THE THICK STENCIL BOARDS.
SUDDENLY MY HEART FEELS LIKE A LITTLE
KID ON CHRISTMAS. MY VOICE IS AS
IMPORTANT AS A MEANINGFUL POP SONG
THE WORLD FALLS IN LOVE WITH.
THIS IS ME AND NOW THESE ARE MY WORDS
LOUDER AND MORE FEROCIOUS THAN EVER.

My Life Through My Eyes

Tiffany Joy Broskoskie

I do not have a disability, I have the ability to see the world differently than most people.

I do not have a disability, I have the ability to hear beautiful sounds that most people do not pause to listen to.

I do not have a disability, I have the ability to smell delicious scents that most people do not slow down to discover.

I do not have a disability, I have the ability to feel various textures that most people do not have the perception to distinguish from others.

I do not have a disability, I have the ability to think in a much more complex way than most people.

I do not have a disability, I have hopes and dreams, passions, hobbies, feelings, and an outpouring of love to give.

I do not have a disability, I have Autism.

I do not have a disability, I have the opportunity to advocate for all people to see the tremendous abilities in me and countless individuals with autism.

Tiffany Joy Broskoskie is 16. She uses RPM to type. Her voice is finally heard after years of trying to find a way to communicate.

Treat me like an Adult!

by Meghana Junnuru

I reopen my wounds for this blog, but only to express and heal them. Sometimes, I am raw from painful memories.

Why me? Why so much pain? Why no one understands? Why do they think I am a baby? It hurts me as to why they do not see me as an adult. On what grounds are my feelings less painful than a typical adult? For many years I have been treated like a child that has no feelings, a child that follows the parent. I was treated in so many ways as disabled. I respect why I was being treated that way, but that's not how I want to be treated. I even want my brother to be treated per his age. In fact, I want every autistic to be treated per their age, not by what they seem on the outside, or based on their potential cognitive age.

I whisper to my brother that it's not our choice to be born this way. I wish that our worst enemies are never in our bodies. Please, offer your advice but don't make decisions for us. I treat myself as an adult and not a child. In our days of sadness we never received a good message that it will be okay. That's because it was assumed that we did not understand anything. We desperately needed counseling. Instead, we got baby care with baths and bedtime stuff. We needed to hear right from wrong. Instead we were not talked to when we made mistakes. We were either distracted or told not to do it or given therapy. Explanations using age-appropriate information were minimal. I tried to learn myself. I repeatedly made mistakes.

On the outside it didn't cause any harm because I was very well protected. But on the inside I tortured myself with each failure and lack of guidance. Guidance where it existed was not age appropriate. I even stayed in depression because it helped to feel self-pity for my condition. I totally understand why this happened. It was because I was a toddler on the outside. I treated myself as more than a toddler but had no way of convincing people that I am not. Opinions of people about me varied, and their treatments varied. Some were better than others.

From this point forward, I never ever want to be treated like a child any more. I treat others with respect and expect the same. I am not angry, just frustrated. Movies are not my thing, but my mother brings me there, treating me like an adult. She takes me to a restaurant like an adult. I tell my mother what I want, and she respects it. I do not get this treatment consistently. We are normal adults inside but stuck in disabled bodies.

Please Note: I am posting this because I am sure every child with autism experiences this at one point or other in their homes, schools or community.

Written by Meghana Junnuru with support from her brother, Chetan. We go by the name "Autism Sibs" and maintain a blog site (www.growourjoy.org) to express our joy for writing.

Chetan Junnuru

Limelight in My Life

by Chetan Junnuru with support from his sister, Meghana

Limelight in my life
growing in my heart
Myriad of ideas
trapped in my brain

Fried by my soul
crimed with anger
Operating in shame
minced in grief

Nipped my heart
drained my spirit
No one knew
how deep it hurt

Braved my heart
to awaken my soul
Pinned myself
to feel other's pain

Loaded with empathy
mopped with love
Trained myself
to cleanse my anger

Visualized a
peace-loving life
With no one
hurt in the end

Tiled myself to
listen to others
Sailed so long
without enough rudders

Limped this far
Forgot my life was hard
Ripped my soul
To find my heart

Kindly see my view
Eloquent is my love
Never judge my life as
molested by anger

Weary and tired
I know no fault
I kindly wait for
forgiveness by all

Listen to my heart
to know what I mean
I love one and all
in sadness and joy

Kindly smear my heart
with your love
To allow my soul
rest in joy

ASK ROB

On Rights

Q: What rights do autistic people have?

A: We want the same rights as any other citizens of the United States. Our lives deserve value because we have enormous value to give the nation and the world. It is not a crime to be different. We are all human beings and want to be treated like human beings, not animals. We are not very different than anybody else. We can be good citizens and want to be treated with respect.

We have seen that many people with autism have been harmed in the past by practices with data which made the practices look useful, but in fact they caused harm. We have a simple life, but behaviorists try and successfully screw up our lives. I have survived and daily recover from treatment NIH and NIMH let be used on me. They were wrong. I ask to keep us safe.

It is hard to do facilitated communication (FC) because group homes, day programs don't allow it in many cases. How can its validity be proved unless fully implemented? Why do people put their jobs and degrees before the people they are supposed to be helping? Then our rights are denied. I want you to know that I have moved forward in life because of FC, and I have proved that rights are attainable with FC.

The time has come for the right of people with autism to have free and open access to facilitated communication. We have been silent long enough. We need to let our words be our voice. I think we should all have the right to communicate, whatever it takes.

I have a team of family and friends who keep me safe and free from harm and make sure my rights are protected. I think for myself and want the same rights as any other citizen of the United States. I am a freedom fighter for all of us.

This Board will work together to help people with autism to have a voice in the 21st century.

Freedom will prevail.

Supported Decision-Making as an Alternative to Guardianship

by Alan Kurtz and Valerie Smith

This article explores an emerging alternative to guardianship referred to as supported decision-making (SDM). SDM is a formal process in which an individual exercises self-determination with support from valued others. SDM has the potential to restore the rights of many autistic people to make important decisions about their own lives while ensuring they have the necessary supports to make those decisions.

Guardianship as an Obstacle to Self-Determination

Autistic individuals, and others with disabilities, are typically provided fewer opportunities than their non-disabled peers to make either everyday choices or major life decisions such as where they live, with whom they live, how their personal money is spent, and what they do during the day. This can, in turn, negatively affect their quality of life. This clearly does not need to be the case. We have known for years that individuals with significant support needs can make important decisions when provided instruction, information, accommodations, and opportunity. At the same time, adults with disabilities, like everyone, often need support when making important decisions.

Restrictions on self-determination can reach their most extreme form when a probate court assigns plenary guardianship in which a guardian has the power to exercise all legal rights and duties on behalf of another. Often, the decision to award guardianship is made without regard to the ability of the person to make decisions when provided adequate supports. In addition, the ruling to remove the individual's legal right to make decisions is rarely re-visited once an external guardian is assigned.

Guardianship laws tend to result in a permanent loss of rights. A recent study found no examples of restoration of rights once terminated. In practice, probate courts tend to work from the assumption that the capacity for individuals to make choices about their own life will not change – either as the result of personal growth or from the provision of effective and caring support.

The assignment of guardianship, especially when it results in the person having little opportunity for control and choice regarding her or his own life, can have significant negative consequences for that person's development and well-being. Reduced opportunities for self-determination can reduce the chances of a person achieving the desired adult outcomes frequently associated with greater choice and control. Fewer opportunities to make decisions can also exacerbate behavior or "symptoms" that ironically were used to justify guardianship in the first place. According to National Core Indicators data, adults with disabilities not under guardianship are more likely to be employed in an integrated job, to have more extensive friendships (i.e., friends beyond family members and paid staff), to date without restriction or to be married, to have unrestricted use of phone and Internet in their homes, and to make choices (or have more input into decisions) regarding where they live, who they live with, their daily schedules, and how to spend their personal funds.

Clearly, if individuals with ASD and other disabilities are to participate more fully in making decisions about their own lives, and experience the improved quality of life typically associated with self-determination, alternatives to the complete abrogation of rights is needed.

Supported Decision-Making

Texas defines SDM in its probate code as follows:

"…a process of supporting and accommodating an adult with a disability to enable the adult to make life decisions, including decisions related to where the adult wants to live, the services, supports, and medical care the adult wants to receive, whom the adult wants to live with, and where the adult wants to work, without impeding the self-determination of the adult. *Texas Estates Code § 1357.002(3)*."

Blanck and Martinis (2015) note that "Although there is no ''one-size-fits all'' model of supported decision-making, it generally occurs when people use one or more trusted friends, family members, professionals, or advocates to help them understand the situations and choices they face so they may make their own informed decisions. As such, supported decision-making mirrors how most adults make daily decisions—whether to get car repairs, sign legal documents, consent to medical procedures, review financial documents, and the like. In each instance, individuals seek advice, input, and information from knowledgeable friends, family, and professionals to make their own informed choices."

Key features of the SDM process include these:

- The person retains full legal capacity;
- The person themself makes the decision. The role of supporters (decision allies) is to assist the person to reach their own decisions;
- there is a relationship of trust between the person making the decision and the supporter(s);
- such a system must be borne of the free agreement of the adult and the supporter(s);
- there is usually a supporting group or network around the person making the decision;
- the role of supporters is to assist the person making the decision to communicate their intentions to others and help them understand the choices at hand; supporters are usually unpaid and could include friends, family, and/or members of the community.

SDM is an established practice in several countries that allows individuals to live self-determined lives by using the support of trusted others to weigh their options while retaining their legal right to decision-making. Countries having adopted some form of SDM include Sweden, South Australia, Germany, Norway, Scotland, England, and Ireland.

In the United States, several states have recognized SDM as a legal alternative to guardianship in statute or their probate code. They include Texas, Delaware, Wisconsin, Alaska, and Maine. In addition, SDM projects have been established in a number of states including Virginia, Maryland, Massachusetts, North Carolina, New York, and Washington D.C. As of 2016, The National Resource Center for Supported Decision-Making (NRC-SDM) had funded a number of small projects including some in Delaware, Indiana, North Carolina, Maine, and Wisconsin (NRC-SDM, 2016).

Implementing SDM on a large scale and in more states will require advocacy, including advocacy for changes in state probate codes. Even in states where it is legally recognized, it will be important to educate family members, transition-aged youth with disabilities, special educators, lawyers, and judges about SDM. Third parties who will be in the position of accepting SDM, such as bankers or physicians, will also need to learn about how it can be used to legally empower people to make important decisions for themselves.

Here are four excellent resources:

- The National Resource Center on Supported Decision-Making: . . .http://supporteddecisionmaking.org/
- Autism Self-Advocacy Network: The Right to Make Choices: New Resource on Supported Decision-Making: . . .http://autisticadvocacy.org/2016/02/the-right-to-make-choices-new-resource-on-supported-decision-making/
- ACLU: Supported Decision-Making and the Problems of Guardianship:. . . . https://www.aclu.org/issues/disability-rights/integration-and-autonomy-people-disabilities/supported-decision-making
- http://jennyhatchjusticeproject.org/

Note: Request references for this article from communicator@autcom.org.

Next Issue

The Communicator promotes autistic voices and points of view, and issues of interest and concern to the autism community. The theme for our next issue is sensory, emotional, and motor regulation and autism. We invite our readers and their friends—particularly autistic people—to submit an article or poem on these or other topics relating to autism.

Submissions may be made on our website, www.autcom.org, or via email to communicator@autcom.org.
Deadline for submissions: January 15, 2019.

We also invite you to propose themes for future issues so that we may feature articles of interest that will inform readers, advocate, provide valuable resources, and move us forward toward a bright, just, and inclusive future. Send correspondence to communicator@autcom.org.

New and Exciting

Books

- *All the Weight of Our Dreams: On Living Racialised Autism*, edited by Lydia X. Z. Brown, E. Ashkenazy and Morénike Giwa Onaiwu, USA, DragonBee Press, An Imprint of the Autism Women's Network, 2017, 500 pages. https://autismandrace.com/
- *Authoring Autism: On Rhetoric and Neurological Queerness* by Melanie Yergeau, Duke University Press, 2017, 312 pages. https://www.dukeupress.edu/authoring-autism
- *In Two Worlds* by Ido Kedar, 2018. http://idoinautismland.com/?tag=in-two-worlds
- *See It Feelingly: Classic Novels, Autistic Readers, and the Schooling of a No-Good English Professor* by Ralph Savarese, Duke University Press, 2018. https://www.see-it-feelingly.com/

Exciting Developments

- Dr. Edlyn Peña, Director of the Autism and Communication Center at Cal Lutheran University, has instituted College Bound Academy, a four-day program to "prepare autistic students, ages 14 to 22, who use augmentative and alternative communication to transition to higher education." Staff for the academy include college student peer mentors, including autistic college students who use letter boards and keyboards to communicate. http//www.callutheran.edu/centers/autism/events/index.html?event_id=4252

We invite our readers to send news of books, films, events, and other developments that we might share in upcoming issues of The Communicator. Send via email to us at communicator@autcom.org. We also invite you to follow us on Facebook and share our postings.

Presentation to Graduate Students in Teacher Education in 2014

by Wally Wojtowicz

Though I am able to communicate my thoughts to you by typing them out on a computer, many other nonverbal autistic students, through no fault of their own, will never experience the pleasure of being able to share one of their thoughts with anyone but themselves. This unfortunate situation is in part a result of a closed minded hierarchy that dominates most of our public and private educational systems at this time. Hopefully, this will change once the educational policymakers wake up to the fact that they had better give serious thought to the exploding numbers of autistic students, both verbal and nonverbal, who will be in need in the coming years of educational services as well as some means to communicate.

You will find as you work with your nonverbal autistic students that those who experience parental support at home, as I have been fortunate enough to have done throughout my life, will do much better adjusting to the world they share with you than will those students who get only minimal support, or no support at home of your attempts at educating them. Parents and teachers have to realize that when working with the autistic population of students, the more effort that is put into the students' education, the more the student will learn. It is up to the parents to grasp the fact that the teachers can do only so much to teach their autistic children in a school setting, and that they, the parents, have to continue on at home each day with the work that the teacher is doing in school.

The profession you have chosen, that of being a special education teacher, will reward you as time goes on, especially when it comes to realizing the rewards you are due from working with the nonverbal autistic population. In the past, I wanted to understand your motives and ideas about your teaching the nonverbal autistic person, though I wanted to do it as I wanted to learn of your world and the reasons why we nonverbal autistic people were always put way at the end of the list of intelligent creatures. Our past performances and reputations should not deter you from trying your best to teach us to communicate in some way, and to teach us age-appropriate subject matter and skills. We perhaps think differently than you do, but this doesn't mean we can't learn and take in information. Pointing this out to you today, from personal experience, is perhaps the best way that I can reach out to you as your equal in the educational field, though I won't have a degree as you will, because "We are all teachers."

About Wally,

A Pioneer

Wally was born December 18th, 1966, in Troy, NY. He was diagnosed at the age of two with "profound, non-verbal autism," at the age of 10 with epilepsy, and at the age of 36 with ALS (aka Lou Gehrig's disease). Wally developed patience and resilience at a young age. Due to the unflagging advocacy and excellent care of his mother and father, Wally was able to thrive, live life to the fullest, and remain at home with his family his whole life. Wally began writing using facilitated communication at 25 and achieved the ability to type independently on both his computer and his eye gaze computer. He used his amazing intellect to write about his experience of being autistic with the hope of enlightening neurotypical people so they could better understand and advocate for people with autism. He wanted to improve the quality of life and access to education and communication for non-speaking autistic people. Wally was invited to present his work at several conferences and classrooms and is a published author. His work has been included in at least six books and numerous publications that have been distributed worldwide. Wally died of ALS on April 6, 2015. He was a wonderful advocate for people with disabilities, a deeply spiritual human being, and a kind, compassionate friend to all who knew him. Wally accomplished more than most people with many fewer challenges. We are so grateful for the prodigious writing he made available to us.

The New Alliance for Citizen Directed Supports

by Nancy Weiss

Director, National Leadership Consortium on Developmental Disabilities, University of Delaware

The Alliance for Citizen Directed Supports is a new international association that has been established in response to a growing need for people with disabilities, their families and the organizations and people who support them to have ways to share ideas and resources toward making the critical shift to quality, individualized, person-directed supports. The Alliance for Citizen Directed Supports advocates for the freedom and human rights of people with disabilities and takes action against anything that limits opportunity and choice. We are a catalyst to transform segregated approaches and services and to champion innovation.

Why a New Association? In September 2015 a group of advocates from across the country began meeting in an effort to address intensifying and well-organized efforts that were cropping up in almost every state to establish intentional gated communities for people with disabilities. People met to plan ways to counter this return to segregation and to address the factors that were keeping services stuck in the past. Participants were concerned that for most people with disabilities, day and community living supports were not significantly different than the kinds of services that had been offered in the mid-seventies.

As a direct result of these discussions **The Alliance for Citizen Directed Supports** was established, as there was recognition that there was no existing organization that welcomed people with disabilities, family members, other advocates and people who work in the disability field to work together exclusively toward citizen-directed supports. The founders of this new association (Marian Frattarola-Saulino, Chair; Gail Godwin, Vice-Chair; Nancy Weiss, Treasurer; and Caitlin Bailey, Secretary), our new board and our growing membership are committed to the goal of individualized, person-directed supports **for all**.

People with disabilities, like all citizens, want to be in charge of their own lives, to choose and have control of their own support, to have fulfilling connections with friends and family, to have romantic relationships, marry and/or have families, to live on their own or with people they choose, and to have jobs and careers that bring in enough money to do the things and have the things that are important to them. **The Alliance for Citizen Directed Supports** Board of Directors works collaboratively to build a vibrant organization that includes and supports the interests of the many people, families, groups and organizations that promote and enable self-direction in the United States and around the world. We proudly support and seek to include everyone who is committed to ensuring that people with disabilities exercise their rights and live fully included lives of their own design.

The Alliance for Citizen Directed Supports will offer an active, inclusive online community and in-person opportunities to share knowledge, ideas and practices to advance individually designed, implemented, controlled and evaluated services and supports. The purpose of The Alliance of Citizen Directed Supports is to make sure this is achievable for all. Go to the website for more information.

We hope you will join! Our website is http://www.citizendirectedsupports.org to learn more. As a welcome, we invite AutCom members to join The Alliance for Citizen Directed Supports at 30% off. For the next two months, use the code AutCom when you join!

Thumbs Up and Thumbs Down

Thumbs UP to United for Communication Choice (UCC) for its ongoing advocacy for communication access. UCC is "a grassroots effort organized by individuals with disabilities, their families, and allies to defend and protect the human, civil, and legal rights of children and adults with disabilities to choose their most effective methods of communication." www.unitedforcommunicationchoice.org

Thumbs UP to the coalition of national civil rights and disability advocacy organizations for its letter to the Board of Directors of the American Speech-Language-Hearing Association (ASHA) expressing serious concerns about their statements on facilitated communication and Rapid Prompting Method, seeking to limit access to communication for individuals who are nonspeaking or who lack reliable speech. https://unitedforcommunicationchoice.org/national-coalition-opposes-ashas-attempts-to-restrict-communication-choice/950/

Thumbs UP to AAPD (American Association of People with Disabilities) for its REV UP! Campaign 2018. "The REV UP Campaign aims to increase the political power of the disability community while also engaging candidates and the media on disability issues. REV UP stands for Register! Educate! Vote! Use your Power!" https://www.aapd.com/advocacy/voting/national-disability-voter-registration-week/

Thumbs DOWN to ASHA's Board of Directors for its revised policy on facilitated communication and its new policy on Rapid Prompting Method (RPM), both of which declare the typing of individuals using those methods not to be their true voices. ("messages produced using FC do not reflect the communication of the person with a disability"; "information obtained through the use of RPM should not be assumed to be the communication of the person with a disability") https://blog.asha.org/2018/08/09/asha-discourages-use-of-facilitated-communication-and-the-rapid-prompting-method/

A Response to “Deej” – A Documentary by D.J. Savarese

by Nick Pentzell

We need role models in the media. We want to see ourselves portrayed in ways that affirm our experience of ourselves and help us imagine lives beyond society’s current limitations. One recent film receiving much deserved attention is the documentary “Deej” (2017, Rooy Media and David James Savarese). Let me state outright that I am not unbiased about the person who is the subject of this film, D.J. Savarese, who is very real indeed. Almost nine years ago at an AutCom conference, in the lobby of the hotel, I first met a literally bouncing teenaged boy whose excitement and happiness lifted him continuously into the air, although I was to discover that his feet were firmly on the ground when it came to compassion. Quickly, D.J. and I became brothers in spirit, visiting at conferences and in Oberlin when he was at school there, and some months ago we spoke together on a panel with a new friend on the spectrum after a screening of Deej. I also have met Rob Rooy, the filmmaker, on several occasions.

A documentary is a document about life, but it doesn’t actually document life itself. Deej was filmed for seven years of D.J.’s life, and over the course of three years the footage was edited into a 72-minute film (and a shorter 53-minute version); D.J. participated in this process, writing the narrative passages and working closely with Em Cooper, the animator. It was a huge undertaking involving a large number of people, and the director and the producers had a great deal to say about the final product. I am aware of differences between what D.J. might have wanted to say with the film and what his collaborators ended up saying.

In his advocacy, D.J. stresses the need for society to change—to become inclusive, but not just to provide supports and accommodations. He wants society to question the structures that create a divisive perception of Otherness. To some extent this is articulated in Deej, yet D.J.—as well as his parents, family, friends, high school, and college—are presented as exceptional: people who overcome odds, adversity, prejudice and, instead, insist on equality as a principle to live by. To some extent this ideal is contrasted in the film with people who are operating within social models in which they are trying to be open to D.J.’s differences but have difficulty thinking outside the boxes that their attitudes, rules, and regulations put them in. However, no one really is portrayed unsympathetically; the boxes that constrain them are those our society is stuck inside. D.J. and his supporters are a model of an outside-the-box approach and put into action D.J.’s call for understanding, acceptance, and equality.

Yet knowing D.J., I think his approach would be a more revolutionary call to action, rather than another film that casts a differently-abled person and supportive team as heroes to emulate. In this respect I believe the film does not document D.J.’s experience of himself. It is a problem inherent with heroicizing people. Heroes are another form of Other and represent the view of an outsider. D.J. and the people around him don’t see themselves as heroes or exceptional. They accept the rightness and logic of assuming competence, providing accommodations, and living inclusively. The film is not at odds with this, but it does not provide an inside view. I think there are ways to escape the Exceptional Individual theme that it perpetuates, and I look forward to films that will explore this.

As much as I want the media to explore de-heroicized options in its portrayal of diffability, I see value, at this point in time, in creating role models. Differently-abled people need to see positive images of themselves, as do inclusively-minded neurotypicals. Therefore, in spite of the aspects in which Deej may stray from being a document of what I believe to be D.J.’s perception of his life and message, I think the film presents a compelling picture of a real-life model of inclusion that has been successful.

The film opens with D.J. typing his words on a laptop. They are the words of a poem, and the motion picture’s photographic realism melts into an animated painting that metamorphoses into images that express the poet’s emotions and the poem’s meaning. Throughout the film, D.J.’s creative inner self, as voiced in his poetry will take a painterly visual form. Here, the first poem is an inner description of an autist’s experience. It is a perception far too often known only in private. It is where D.J. started his life before he could communicate and, heartbreakingly, where many of our brothers and sisters will remain throughout their lives. It is the point of departure for the viewer.

During moments in his everyday life, D.J. is revealed as a young man working hard to increase his independence as a communicator, a mute person learning to shape sounds, a person without a developed sense of living in his body receiving training and feedback to increase his coordination and focus. However, he is not his diagnosis; instead, D.J. explains how his neurological differences present a daily obstacle course he must problem-solve his way through. I especially like how D.J. reiterates throughout the film the way in which anxiety manifests itself in ways that take us out of the moment—frozenness, silliness, moving around or escaping, struggling physically, becoming blind to the people around us—even while we desire to contain ourselves and engage in a situation. D.J. also contends with a rocky past: neglect, desertion, abuse by his birth mother and the foster care system before he was adopted by Emily and Ralph Savarese.

Diffability is always there, as comrade and antagonist, but I pretty much think everyone’s life has restrictions and requires accommodations—it’s just that many of these have become accepted by society and go unnoticed as such. I yearn for a day when autism will be part of the fabric of everyday life, and I think Deej gives us a glimpse of what this can be like.

Principles of the Autism National Committee

As a member of the Autism National Committee I endorse for all people with autism spectrum differences, 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 individualsí 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 individualís 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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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

Attention AutCom Members

Consider requesting extra copies of this newsletter in print to share with your legislator, DD Council, local Arc chapter, families who might want to join AutCom, your child's teacher, and others. Email Barbara Cutler, bccutler@aol.com, to request additional copies. Be sure to include your mailing address.

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