

RESPONSE TO DEEJ by Nick Pentzell

Reprinted from *Wordgathering*, Volume 12, Issue 1 (March 2018)
http://www.wordgathering.com/past_issues/issue45/pentzell.html

We need role models in the media. My friend Matt and I went to see *Swim Team* (2016) this past summer, the film about the Jersey Hammerheads—teen swimmers on the autism spectrum—and left the theatre discussing this problem: "Too much about parents." "We need films that take our perspective." "This film could be a first step for neurotypicals to understand people on the autism spectrum, but it's just another work that shows us from other people's points of view." We want to see ourselves portrayed in ways that affirm our experience of ourselves and help us imagine lives beyond society's current limitations.

The ABC television network has taken a significant step in this direction with *The Good Doctor*, the fictional story of Sean Murphy, a first year surgical resident, who perceives medicine uniquely because of his autism. His problem-solving skills take atypical routes, often involving his hyper-focus, attention to detail and structure, sensory sensitivities, and unswerving insistence on what he knows to be right—spectrum characteristics many of us share that here are presented as strengths that can save lives and demonstrate the value of neurodiversity. We also see Sean struggle, as he is sometimes rigid, unaware of verbal nuance and social cues, or physically inhibited or frozen by emotions, distractions, and thoughts which impede many of us on the spectrum as movement disturbance disorder. I tune in every Monday night, loving how this character pushes the boundaries in understanding autism, both in the context of the world of the hospital story and (I hope) in the minds of real world television viewers. Yet Sean is presented as an exception, almost an autistic super hero at this point in time. (I had a doctor admit to me privately that he possibly had Asperger's*, but for most professionals a spectrum label seems a liability; maybe *The Good Doctor* will point more closet Aspies and Auties to "come out" and validate our value to society.) Sean also is a fictional character played by a neurotypical actor. The show is a dream of what real life can be, but it is not real.

Which brings me, with much introduction, to the film that is the focus of this response article: *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.

I collaborated on a short video—*Outside/Inside* (2002)—with my stepmother, Gwen Waltz, and I also had a conversation with D.J. at a conference when Rob was filming, so I have some idea how a documentary actually is very artificial. You become self-conscious as you are filmed. You know how much of what is shot is edited out and that

a snippet of an event doesn't tell the whole story. Collaboration involves sharing what is said and how it is presented, therefore material from your own life is interpreted by people who don't always share your point of view. A documentary is a document about life, but it doesn't actually document life itself. My documentary was six minutes long, put together in a few months, and I wrote a script, chose what I wanted for the shots, and helped edit everything together, so over all I had a lot of control. *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, but he was not involved in the camerawork and had limited input over the editing and structure of the film. 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. Compared to my experience, I think D.J. shared authorship to a lesser extent than I did, and 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.

I am aware there is a progression in the way that people considered Other enter society in media portrayals, as if it were a process of being accepted as equal. With diffability the evolution seems to have been variations on—or combinations of—stories about 1) differently-abled people who either are frightening, menacing outcasts, or else angelic beings sent to teach lessons to mere mortals, 2) poor suffering parents and caregivers who deserve society's pity and assistance, 3) exceptional heroic parents and caregivers who help poor suffering people with diffabilities lead better lives, 4) exceptional heroic people with diffabilities who overcome adversity, 5) characters who happen to be differently-abled, but Disability is not the focus of their roles. Beyond this we would

progress to 6) plots in which we are merely people living in a (changed) society in which it is recognized that we all have differences and as human beings deserve equal rights, accommodations, and supports that enable all people the opportunity to pursue their greatest potential.

As much as I want the media to explore de-heroicized options in its portrayal of disability, 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. Unlike Sean Murphy and the people at the hospital where he works, D.J. and all the people in his orbit actually exist and to an admirable extent have overturned society's paradigms about disability. Creative works become entities separate from their creators, moving on in unanticipated directions, and affecting and influencing people in ways uncontrolled by their authors. *Deej* will have a "life of its own" and is an important document in its own right.

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 autistic's experience. It is a perception far too often known only in private, the cause of the damned puzzle-piece that neurotypicals use as a symbol for autism's differences. 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.

The inclusive setting of D.J.'s high school in Grinnell, Iowa, contrasts as the film's entryway into his everyday world. We see him participating in a class, a right too often denied to differently-abled students, presenting a powerpoint assignment in which he discusses the brain's neurological wiring. We see the way in which this topic connects to D.J.'s autism. In a scene with his parents at home, D.J. describes his supported typing, via his computer voice, as he talks with Rob, the filmmaker. 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.

Difference infuses everything that D.J. does, but in another sense it is also background to the things that he accomplishes. He writes and assistant-directs a play. He spends time with his friends and family, goes to Washington, D.C., with his cousin, visits college

campuses and is accepted to Oberlin, wins a competitive scholarship, and graduates from high school. D.J. addresses the fears we have in separating from our parents as we move toward supported independence in our lives. He meets a role model who is living independently at an Iowa college, and they develop a loving relationship. He moves to Oberlin and into a college dorm by degrees, especially supported along the way by his mother (and one of the coolest women I know), Emily. As he adjusts to college life, D.J. exercises independence with Rob, and at one point in the film a title informs us that they took a break from filming. I could be describing the occurrences in many a student's life, yet we see it happening (not always easily, but always moving forward) to a student who challenges the people around him to become aware of a new way of being.

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.

*I published this review before revelations about Hans Asperger's crimes against people on the autism spectrum became news later in 2018; as a result, I have dropped "Asperger's" and "Aspie" from my vocabulary (except to quote earlier works). Since this review is a reprint, I have let it stand as-is.

*Nick Pentzell is a graduate of Delaware County Community College in Media, Pennsylvania, where he earned his Associates Degree in Liberal Arts. A presenter at disability conferences and workshops, he has written about autism in **The Philosophy of Autism** (2013), **Real People, Regular Lives** (2011), **Sharing Our Wisdom** (2003), and in journals, including **Wordgathering**, **Disability Studies Quarterly**, AutCom's **The Communicator**, and **The Other Side**. His award-winning video, **Outside/Inside** (2002), has been shown at disability film festivals worldwide.*

March 21, 2018