

Struggling to Communicate: Autism and the Media  
By Rebecca Lay

Most Americans could not tell you that autism is the fastest-growing developmental disability in the United States, with approximately one in 150 children affected.<sup>1</sup> In a country where recent presidential candidate John McCain confuses Autism with Down syndrome,<sup>2</sup> this isn't surprising. Autism spectrum disorder, which includes autistic disorders on a mild to severe scale as well as Asperger syndrome, is characterized by "developmental disabilities that cause substantial impairments in social interaction and communication and the presence of unusual behaviors and interests."<sup>3</sup> Although coverage of the Autism Community has gotten better over the past decade, the media "grossly underreports the challenges of autism."<sup>4</sup> This results in a lack of full understanding among the general population, which creates a vicious cycle of misinformation, leading to intolerance.

A conflict in the motivation of the media contributes to the lack of accurate information about autism. Major newspapers and news outlets depend on readership and viewers to lure their advertisers. The goal of educating the public on autism becomes entangled with the media's need to focus on what the public wants to hear. "You can't educate or correct the misconceptions if the media's interest is only in stories that will buy time from advertisers. The bottom line is always there in terms of stories that the media will cover,"<sup>5</sup> says Julie Azuma, the mother of a child who was diagnosed with autism and the founder of Different Roads to Learning, a website that provides educational aids that support the Autism Community.

Kim Stagliano, the mother of three children diagnosed with autism and the managing editor of Age of Autism, a daily web newspaper focused on the Autism Community, agrees, noting that the media "tends to focus either on tragedy or feel good stories."<sup>6</sup> Autism spectrum disorders are relatively mysterious in that they affect individuals in many different ways and on a wide scale. Additionally, there is no known definitive cause or cure for autism spectrum disorders.<sup>7</sup> This epidemic of a disease that baffles the medical community does not present an easy feel good story with a happy ending. "Autism...frightens people, with no documented cause so they avoid it,"<sup>8</sup> says Kim Stagliano.

But when the media doesn't avoid the topic, it tends to sensationalize the stories for its viewers. This can be witnessed in a simple online video search on CNN for the keyword "autism." The top video results, sorted by "most relevance," include a video named "First look at lost home," in which "a family with an autistic child, losing their home to a wildfire presents

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<sup>1</sup> Lara Salahi, "Life After Autism Diagnosis," ABC News 4 Nov. 2008: retrieved 3 Dec. 2008 <<http://abcnews.go.com/Health/AutismNews/story?id=6173652&page=1>>.

<sup>2</sup> "Did John McCain confuse autism with Down syndrome?," LA Times 16 Oct. 2008: retrieved 2 Dec. 2008 <<http://latimesblogs.latimes.com/thedishrag/2008/10/did-john-mcca-1.html>>.

<sup>3</sup> "Autism Spectrum Disorders Overview," Centers for Disease Control and Prevention 9 Feb. 2007: retrieved 3 Dec. 2008 <<http://www.cdc.gov/ncbddd/autism/overview.htm>>.

<sup>4</sup> Kim Stagliano, Personal interview, 5 Dec. 2008.

<sup>5</sup> Julie Azuma, Personal interview, 3 Dec. 2008.

<sup>6</sup> Kim Stagliano, Personal interview, 5 Dec. 2008.

<sup>7</sup> "Autism Spectrum Disorders Overview," Centers for Disease Control and Prevention 9 Feb. 2007: retrieved 3 Dec. 2008 <<http://www.cdc.gov/ncbddd/autism/overview.htm>>.

<sup>8</sup> Kim Stagliano, Personal interview, 5 Dec. 2008.

special challenges,” “Karate therapy,” in which “karate has become a sort of therapy for one autistic boy,” and “Father and son adrift at sea,” in which “Dr. Sanjay Gupta reports on how a father and his son who has autism survived treading water at sea for 14 hours.”<sup>9</sup> “The media is only interested in a bleeding heart story or a miracle,” Azuma says.<sup>10</sup> The video “When Jerry Met Mary” tells the story of two highly functioning middle-aged autistic adults who met at a support group and fell in love. Jerry describes himself as “almost normal” and calls his relationship with Mary a “miracle.” Both are also genius savants, Jerry an expert mathematician and Mary a musical and artistic genius.<sup>11</sup>

Occasionally the media presents a child who suffers from severe complications due to autism, but manages to balance out the story with an extreme gift and message of hope. For example, 60 Minutes presents “Catching Up With Rex,” a segment about an autistic child who, although severely impaired, is a prodigious savant in music. “Rex was born blind with brain damage so severe, his mother Kathleen was told he may never walk, talk, or do much of anything,” Lesley Stahl narrates at the beginning of the video. The segment continues to show Rex’s musical genius and his “new friends” at a special school for savants, who also play music with prodigious talent. Despite all odds, he walks and talks and even reads. The last clip shows Lesley Stahl improvising a duet with Rex, both of them laughing and smiling.<sup>12</sup>

However, Julie Azuma notes, “both types of children [autistic and autistic with savant syndrome] have caused a rate of divorce of 75% in families with autistic children.”<sup>13</sup> No family touched by autism is saved from grief and hardship. Savant Syndrome, a condition in which an individual’s handicaps and developmental disabilities are contrasted with extreme genius in a certain skill, is exceptionally rare. “There are fewer than 100 reported cases of prodigious savants in the world literature” and today “probably fewer than 25 prodigious savants living.”<sup>14</sup> Despite the statistics, the media tends to highlight these rare cases, or as Kim Stagliano says, “They tend to show the ‘tricks’... swishes on the basketball court... math geniuses.”<sup>15</sup>

When the media doesn’t sensationalize stories about autistic individuals, it inaccurately characterizes them, sometimes contributing to existing stereotypes and common misconceptions in society. Although the autism spectrum disorders “can vary---from gifted to severely challenged,”<sup>16</sup> the media mostly shows high functioning individuals. “The media tends to represent children and young adults who have language and some skills when there are many

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<sup>9</sup> Sampling of Video Search Results: retrieved 6 Dec. 2008

<<http://search.cnn.com/search?query=autism&type=video&sortBy=date&intl=false>>.

<sup>10</sup> Julie Azuma, Personal interview, 3 Dec. 2008.

<sup>11</sup> “When Jerry Met Mary,” reported by Lesley Stahl, 60 Minutes, 18 Feb. 2007: retrieved 6 Dec. 2008 <[http://www.cbsnews.com/video/watch/?id=2491535n%3fsource=search\\_video](http://www.cbsnews.com/video/watch/?id=2491535n%3fsource=search_video)>.

<sup>12</sup> “Catching Up With Rex,” reported by Lesley Stahl, 60 Minutes, 24 Nov. 2008: retrieved 6 Dec. 2008 <[http://www.cbsnews.com/video/watch/?id=4628663n%3fsource=search\\_video](http://www.cbsnews.com/video/watch/?id=4628663n%3fsource=search_video)>.

<sup>13</sup> Julie Azuma, Personal interview, 3 Dec. 2008.

<sup>14</sup> Darold A. Treffert, MD, “The Savant Syndrome: Islands of Genius,” The Wisconsin Medical Society 2008: retrieved 6 Dec. 2008 <[http://www.wisconsinmedicalsociety.org/savant\\_syndrome/savant\\_articles/islands](http://www.wisconsinmedicalsociety.org/savant_syndrome/savant_articles/islands)>.

<sup>15</sup> Kim Stagliano, Personal interview, 5 Dec. 2008.

<sup>16</sup> “Autism Spectrum Disorders Overview,” Centers for Disease Control and Prevention 9 Feb. 2007: retrieved 3 Dec. 2008 <<http://www.cdc.gov/ncbddd/autism/overview.htm>>.

children who don't have language and have very difficult behaviors," Azuma says, referring to behaviors that include "head banging, aggressive behavior, feces issues, screaming and lack of self control."<sup>17</sup> For parents of children who are on the severe end of the autism spectrum, these behaviors represent what Stagliano refers to as "the day-to-day grind,"<sup>18</sup> something that is rarely shown in media coverage.

An online search on MSNBC with the keyword "autism," is all too telling. In a sampling of the first ten video results, sorted by relevance, and without counting duplicates, only one video actually shows at home everyday footage of an autistic child and her family. None of the ten videos show severe symptoms or behavior associated with autism.<sup>19</sup> "The media films for an hour to get a 10 second clip that doesn't define anything close to what families of children diagnosed with autism live through each day. [They do not define] what the house looks like, where there's plexiglass instead of glass, where the walls are either reinforced or padded, where the bathroom has picture grams all over, where there is a visual schedule by the door, where there's a room or space just to work with the child," says Azuma.<sup>20</sup>

This presentation of high functioning autistic individuals, while avoiding those with more severe symptoms only allows readers and viewers to glaze the surface of the problems associated with these behaviors. Since there are usually no obvious physical symptoms of the disease, children with autism can look to the untrained eye as though they were simply poorly disciplined normally functioning children. "That type of interview [with a high functioning autistic individual] would lead people to think that autism isn't so hard," says Kim Stagliano adding that viewers would think to themselves, "'Look at that person, she can talk, think and do the same things as my daughter or sister.'"

It is misconceptions such as these that fuel public intolerance, which then spreads to others. On July 16th, 2008, Michael Savage raised concerns among the Autism Community when he argued on his radio talk show The Savage Nation that in "99 percent of the cases [of autism spectrum disorder]...they don't have a father around to tell them, 'Don't act like a moron. You'll get nowhere in life. Straighten up. Act like a man. Don't sit there crying and screaming, idiot.'" The Savage Nation reaches millions of listeners, with "more than 350 stations nationally."<sup>21</sup> Members of the Autism Community were concerned with the possible effects of Savage's statements. "Autism experts say Savage's statements threaten to alter the public's understanding of the disorder,"<sup>22</sup> noted ABC News.

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<sup>17</sup> Julie Azuma, Personal interview, 3 Dec. 2008.

<sup>18</sup> Kim Stagliano, Personal interview, 5 Dec. 2008.

<sup>19</sup> Sampling of Video Search Results: retrieved 6 Dec. 2008

<<http://www.msnbc.msn.com/?q=autism&search=search+site&submit=Search&id=11881780&FORM=MSNBC&os=0&gs=1&p=1&adunitid=939&propertyid=3501>>.

<sup>20</sup> Julie Azuma, Personal interview, 3 Dec. 2008.

<sup>21</sup> Jacques Steinberg, "Savage Stands by Autism Remarks," The New York Times 22 Jul. 2008: retrieved 3 Dec. 2008

<<http://www.nytimes.com/2008/07/22/business/media/22sava.html?scp=2&sq=michael%20savage&st=cse>>.

<sup>22</sup> Dan Childs, "Savage's Comments Infuriate Autism Community," ABC News 21 Jul. 2008: retrieved 3 Dec. 2008 <

<http://abcnews.go.com/Health/AutismNews/Story?id=5419861&page=1>>.

In his recent book “Why We Suck: A Feel-Good Guide to Staying Fat, Loud, Lazy and Stupid,” comedian Denis Leary also helps fuel incorrect perceptions about autism. “There is a huge boom in autism right now because inattentive mothers and competitive dads want an explanation for why their dumb-ass kids can't compete academically...I don't give a [bleep] what these crackerjack whack jobs tell you - yer kid is NOT autistic. He's just stupid. Or lazy. Or both,”<sup>23</sup> he writes. Historically, autism was thought to be the result of poor parenting. After first identifying the disorder in 1943, psychiatrist Dr. Leo Kanner theorized that emotionally cold mothers were to blame. The term “refrigerator mother” was coined.<sup>24</sup> Although it is now accepted among the medical community that there is no known definite cause or cure for the disorder,<sup>25</sup> this spread of inaccurate information reinforces wrongly directed blame in the public's minds today. “I've been in those shoes. I have been called a bad or permissive parent because of the behaviors of my own child.” Azuma says.

Although the public has come a long way in accepting those with mental disorders, people with autism are still seen and presented in the media as unequal members of society. Some reporters even refer to them with sub-human connotations. In a movie review of “The Black Balloon,” the story of how an “autistic son reveals family shame and strength,” New York Times writer Stephen Holden refers to Charlie, the autistic character, as “feral” and a “desperate wild animal.”<sup>26</sup> In a Nightline Special Autism Report called “Love is Complicated Even for the Autistic,” reporter John Donvan walks down a long road with Paul, an adult who suffers from an autistic spectrum disorder. As he questions Paul about his unrequited love for an older woman, a voiceover says, “Who knew that a man with autism could suffer the pain of a broken heart.” Throughout the video, he continues questioning, “Does it even make sense to say that an autistic man is in love? Do autistic people love the same way as you and I do?”<sup>27</sup> Donvan's confusion about whether an autistic person has regular human emotion reflects a misconception and reinforces it. As Time Magazine notes, “Other classic symptoms--a lack of emotion, an inability to love--can now be largely dismissed as artifacts of impaired communication.”<sup>28</sup> “They are people!” Stagliano says when asked about this misconception, “Total myth. Not knowing how to express it doesn't mean it's not there! They aren't psychopaths, devoid of emotion.”<sup>29</sup>

The future of coverage on autism depends on communication. The Autism Community needs to be accurately and more thoroughly represented. The vicious cycle witnessed with

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<sup>23</sup> “Denis Leary Slams Autism As A Joke,” The Huffington Post 15 Oct. 2008: retrieved 3 Dec. 2008 <[http://www.huffingtonpost.com/2008/10/15/denis-leary-slams-autism\\_n\\_134749.html](http://www.huffingtonpost.com/2008/10/15/denis-leary-slams-autism_n_134749.html)>.

<sup>24</sup> James R. Laidler, MD, “The ‘Refrigerator Mother’ Hypothesis of Autism,” Autism Watch 15 Sept. 2004: retrieved 3 Dec. 2008 <<http://www.autism-watch.org/causes/rm.shtml>>.

<sup>25</sup> “Autism Spectrum Disorders Overview,” Centers for Disease Control and Prevention 9 Feb. 2007: retrieved 3 Dec. 2008 <<http://www.cdc.gov/ncbddd/autism/overview.htm>>.

<sup>26</sup> Stephen Holden, “Autistic Son Reveals Family Shame and Strength,” The New York Times 5 Dec. 2008: retrieved 6 Dec. 2008 <<http://movies.nytimes.com/2008/12/05/movies/05ball.html?scp=3&sq=autism&st=cse>>.

<sup>27</sup> “Love is Complicated Even for the Autistic,” reported by John Donvan, ABC News, 17 June 2008: retrieved 3 Dec. 2008 <<http://abcnews.go.com/video/playerIndex?id=5055527>>.

<sup>28</sup> Claudia Wallis, “Inside the Autistic Mind,” Time 7 May 2006: retrieved 3 Dec. 2008 <<http://www.time.com/time/magazine/article/0,9171,1191843-3,00.html>>.

<sup>29</sup> Kim Stagliano, Personal interview, 5 Dec. 2008.

Michael Savage and Denis Leary's public comments must be broken so that levels of tolerance and acceptance of the Autism Community can continue to grow. Julie Azuma shows hope for the future in her belief that "the attitude towards the autism community is changing and more people are understanding and grateful that they have mainstream children."<sup>30</sup> However, media coverage must help facilitate this change through educating the public. Only when the media decides to take an accurate look at the Autism Community from the perspective of its actual members, and not one that is filtered through the eyes of its viewers will this positive change occur.

"There are few people in the media that understand autism. It's impossible to have a grip on the disorder unless you live it,"<sup>31</sup> says Azuma. More in-depth coverage of everyday life in a household affected by autism without censoring more severe behaviors and symptoms would help viewers at least begin to "have a grip." As Julie Azuma strives to communicate with her website Different Roads to Learning, the public needs "to let parents know that we are in total understanding of the lives they live and the issues that they face."<sup>32</sup> Along with this in-depth coverage, a more representative sampling needs to be taken from the full spectrum of the autism spectrum disorders. Kim Stagliano believes that not only should more interviews be held with the actual individuals diagnosed within the autism spectrum, but with "people at all levels of impairment."<sup>33</sup> With the website Age of Autism, Stagliano attempts to "expose the myths and outright lies" and "educate the public about the reality of autism from inside."<sup>34</sup>

The Autism Community hopes that with more education and awareness, acceptance and support will follow. "Autistic people as well as people with any disability should gain acceptance in the community, the same as those who were involved in the civil rights, gay rights and feminists movements in the 60's," says Azuma.<sup>35</sup> After the public begins to fully recognize these struggles, surely they will be able to accept those who are affected by this mysterious disease and support them. Although psychologist Peter Gerhardt has seen a positive change in research, education, and tolerance in the past decade, he still strongly reaffirms that "we're settling for less than mediocre. Let's start settling for good for a change, and then I'll argue towards excellence."<sup>36</sup>

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<sup>30</sup> Julie Azuma, Personal interview, 3 Dec. 2008.

<sup>31</sup> Ibid.

<sup>32</sup> Ibid.

<sup>33</sup> Kim Stagliano, Personal interview, 5 Dec. 2008.

<sup>34</sup> Ibid.

<sup>35</sup> Julie Azuma, Personal interview, 3 Dec. 2008.

<sup>36</sup> "Adults With Autism," reported by John Donovan, ABC News, 10 May 2007: retrieved 3 Dec. 2008 <<http://abcnews.go.com/video/playerIndex?id=5179205>>.