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The Autistic Genocide Clock

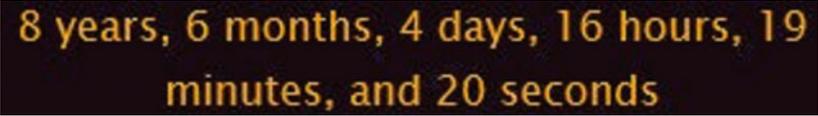
Meg Evans

Alarm Bells

When I first thought about creating a Star Trek fanfiction website in the summer of 1999, I had no idea that the site would later become known for a ten-year countdown timer warning of a potential genocide in the making. That summer, everything in my life seemed to be going very well. I had just found a good job after staying home with my kids when they were little, and fun stories were all I had in mind for the Ventura33 website—so named because I got the idea for it while driving along California’s Highway 33 in Ventura, known formally as the City of San Buenaventura (Fig. 9.1).

The topic of autism, along with society’s views of it, was not on my radar at that point in time. Although I had seen the word used in reference to me as a child, I thought it simply had to do with early childhood language

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8 years, 6 months, 4 days, 16 hours, 19
minutes, and 20 seconds

Fig. 9.1 The Autistic Genocide Clock by Meg Evans

development. I knew that the fact I'd learned to read and talk at about the same time was unusual, but I didn't understand what relevance it might have in adult life. I was an early reader, while others in my extended family had been slow to speak, and I simply took it for granted that everyone developed at their own natural pace. People sometimes told me that my speech sounded a bit odd, which I attributed to living in different parts of the country as a child and getting my regional accents muddled. I didn't see that as significant either.

Sometime toward the end of 2002, I began to notice that there were sensational stories cropping up in the mainstream media about "Asperger syndrome," a now-outdated term that meant autism without a speech delay. I had not seen that term before and did not identify with it. The stories all followed the same general pattern of describing children who behaved in peculiar ways, thus supposedly causing their parents to lead lives of intolerable misery. At first, I paid very little attention to that narrative, dismissing it as a ridiculous pop-psychology fad that couldn't last long. After all, raising quirky children was certainly nothing new in the history of parenting. The children described in those stories didn't strike me as all that odd anyway.

Far down in my subconscious mind, though, a few dots started to connect. By late 2003, the picture had grown clear enough that my internal alarm bells were sounding. Those sensational articles hadn't gone away, but instead were showing up more often. Their scope was not limited to children but also encompassed autistic adults, who were commonly described as freakish, incapable, barely human, and unsupportable burdens on society. Internet searches only turned up more of the same, and I began to realize that I was looking at a dangerous mass hysteria.

Aspergia

One site that I came across during those searches was an exception—the UK-based forum Aspergia. Created in 2002, it aimed to spark critical discussion of society’s attitudes toward autism by creatively framing the issue in terms of speculative fiction. Aspergia’s featured story asked readers to consider: What if—rather than being defined by a medical label—autistic people were an ethnic minority group, descended from an ancient tribe with a recognized history and culture? Would society then be willing to accept, respect, and accommodate their differences? And if so, then why wasn’t that happening in real life, and what needed to change?

Although the website’s name obviously was derived from the term Asperger syndrome, the site was not exclusive to those who had received that particular diagnosis. The forum community welcomed all participants equally and sought to encourage a respectful conversation about what disability meant in relation to autism. Some members came to the site believing that autism was inherently disabling, while some did not view themselves as having a disability at all. Many informative discussions took place regarding the social model of disability, which holds that people become disabled not as the inevitable result of a physical or mental condition, but because socially constructed barriers prevent them from fully participating in society.

The existence of a forum where autism was discussed in terms of the social model of disability may not seem remarkable by today’s standards; but at the time, many people had never seen anything like it. Some had grown up internalizing ugly stereotypes and myths, believing that they never would have a place in society. Although others had a vague sense that all was not as it should be, they couldn’t quite say how. The conversation on Aspergia challenged participants to give more thought to the prevailing cultural assumptions. It was a daunting and often uncomfortable process of consciousness-raising.

Because I found it hard to understand why the culture was full of stories about autism that diverged so fundamentally from my own view of the world, I did some reading. I learned the awful history of what had been done to people with developmental disabilities in the twentieth century—eugenics, institutions, exclusion from schools and other public places.

Slowly it dawned on me that when I had changed schools several times as a six- and seven-year-old, the reason hadn't been—as I naively assumed at the time—to try out different schools and see which one was a good fit, like trying on clothes at the store. My mother, when I asked her, confirmed that the school administrators had told her I was not welcome to stay, and so she kept trying until she found a school that would keep me. This was a few years before the federal government required schools in the United States to educate all children.

Aspergia's forum closed in July 2004. The site was a casualty of its own success, in that it had grown much faster than its administrator—who called himself Edan—had anticipated. As a consequence, the site never had enough moderators to deal with the frequent arguments and flame wars that inevitably resulted from challenging people's worldviews.

Continuing the Conversation

Several former members of Aspergia, who believed that the conversation needed to continue, started building their own websites. The most successful in terms of sheer numbers was Wrong Planet, a forum site created by two teenagers, Alex Plank and Dan Grover, who envisioned a welcoming social space. Discussion of the more politically charged issues often took place in a forum in the UK called Aspies for Freedom (AFF), founded by Amy and Gareth Nelson. AFF was designed to include not only autistic activists but also parents concerned about their children's future.

On the AFF parenting forum, non-autistic parents sought advice to help them better understand their children's needs. Autistic members offered suggestions, while also discussing civil rights concerns in other areas of the site, where parents were welcome to participate if they wished. I took part in some of these conversations under my forum nickname of Bonnie Ventura. Describing myself as a person who belonged to a multigenerational autistic family, I gently encouraged parents to recognize their own autistic traits and to trust their instincts in raising their children. Among those who joined AFF in early 2005 was Kevin Leitch, a British parent who soon built the Autism Hub blog aggregator with the goal of constructively bringing together parent bloggers and autistic activist bloggers.

I'd had the Ventura33 story website for about five years by then, and it had grown into an archive that included not only my stories but also those of several other contributors. Inspired by Aspergia's use of fiction as a catalyst for discussion of autism in the context of disability rights—a concept that was becoming more commonly known as neurodiversity—I decided to create a page on Ventura33 for that purpose. I put out a call for stories featuring autistic characters and others with neurological differences in the Star Trek universe, which I posted not only on fanfiction writers' lists, but also on AFF and other autistic community forum sites.

My goal for the neurodiversity page was simply to encourage my readers to think a little farther outside their cultural boxes. I didn't anticipate that Ventura33 would play a major role in bringing together autistic activists to organize for civil rights in real life. Rather, I had in mind that the stories would promote reflection and constructive dialogue as a counterweight—if only a small one—to society's unthinking repetition of autism myths.

Countdown

Then I came across a disturbing news article published on February 23, 2005, which left me with a greater sense of urgency. Entitled “Autism research focuses on early intervention,” it began by discussing studies of siblings' behavior and then moved on to government funding and genetics. The author interviewed Dr. Joseph Buxbaum, head of the Autism Genome Project at the Mount Sinai School of Medicine, and discussed his expectation of “major progress in identifying the genes associated with autism in the next decade” [1].

That in itself did not immediately strike me as cause for concern—after all, one might expect a research scientist to be optimistic about work in progress, and genetic research could potentially have many different aims. But then I scrolled down a little farther and found this unambiguously stated prediction:

Buxbaum says there could be a prenatal test within 10 years.

What I found most unsettling about this statement was not simply the fact that it had been made, but that the worldview from which it sprang was devoid of meaningful examination. The overall tenor of the article—and, indeed, of the general public discourse surrounding autism at the time—was that everyone agreed the world should not have autistic people in it. The only question, as many saw it, was how to reach that goal. An entire layer of critical inquiry into the underlying assumptions had been effectively short-circuited.

I started composing a response to post on Ventura33, along with a link to the article. I wrote that the possibility of a prenatal test for autism raised significant ethical concerns. This was not an issue of abortion politics, as I saw it; rather, it had to do with informed decision-making and the value that our society places on different kinds of people. Government funding to develop a prenatal test, together with stereotypes and misinformation in the media that characterized autism as a devastating burden to families and society, gave rise to a coercive environment in which pregnant women would not be able to make truly informed decisions.

Because many autistic people go undiagnosed, I wrote, the total number worldwide was likely to be much higher than was generally believed—perhaps over 100 million. (More recent scientific estimates have confirmed that this higher number is in fact likely.) This would be equivalent to about one-third of the US population, or the total populations of the UK, Canada, and Australia combined. As such, prenatal testing for autism would amount to eugenics on the largest scale in human history.

Ending with a call to action, I asked my readers to visit other autistic advocacy websites and, if possible, to create their own; to get involved in real-life advocacy events; and to contact policymakers to express their views. Consistent with the ongoing dialogue in the AFF forum community, I urged parents to work toward building a society where their children's lives would be valued.

My working title was “Autism Research and Prenatal Testing.” That title seemed too bland, though; it didn't convey a feeling of urgency. I asked my husband, who is a software developer, to add a timer at the top of the page counting down 10 years from the date of the news article. After he added the code, “The Autistic Genocide Clock” was launched on May 22, 2005.

Drawing Attention

I posted the first group of stories on the neurodiversity page in June 2005 and got some comments by email. One of them was a question from a student named Ari Ne’eman—was I involved in any real-life civil rights organizations focusing on autism? No, I was not, I answered; but in my opinion, such organizations were much needed.

Because Ventura33 was only a small fanfiction website, I wasn’t expecting either the neurodiversity page or the clock page to get much attention. The site was so small, in fact, that my husband had put both it and his personal blog on a server in the basement using our basic residential Internet connection. The server was just an old, slow desktop computer that I had bought as surplus from my employer for 20 dollars, but that was good enough because we got so little traffic.

It took me a while to realize that my site had in fact drawn more attention than I’d anticipated. In late 2005 and early 2006, I did occasional Google searches on the word “neurodiversity,” looking to see what new activist websites had emerged. I noticed that the Ventura33 neurodiversity page was consistently in the top ten results. At first, I assumed that was because the concept was still new enough that there hadn’t been much written about it yet.

Then one day, my husband said, “Hey, Meg, did you know that so many people have been deep-linking to your clock page that we’re running out of bandwidth?”

I told him, no, I hadn’t been aware of that. My husband was keeping detailed statistics, though, and there was no doubt the clock page was getting most of the increase in traffic. Eventually, we ended up moving our websites to a virtual private server.

Autism Hub

Meanwhile, Autism Hub had gotten underway; there were about fifteen blogs in the aggregator in early 2006, and it grew rapidly from there. Several of its members had medical or other science backgrounds, and the early Hub posts often warned about the dangers of quack treatments purporting

to cure autism. Disability rights topics were a large part of the discussion too. The Hub's initial members included Joelle (then Joel) Smith, whose list of autistic murder victims was a precursor to the Disability Day of Mourning.

The Hub's parent bloggers—one of whom was Estée Klar, a Canadian art curator who founded The Autism Acceptance Project and promoted inclusion by way of the arts—often wrote about happy moments in their everyday lives. At that time, images of autism in the mainstream media had been so relentlessly negative that even these simple, cheerful posts about enjoying family life went a long way toward changing the narrative for the better.

In May 2006, the Hub's bloggers erupted in outrage following the release of a video entitled *Autism Every Day* by Autism Speaks, which was then a newly formed organization. The video depicted the lives of families with autistic children as a fate literally worse than death; one parent featured in it said that she had thought about driving off a bridge with her autistic daughter in the car. The producer, Lauren Thierry, suggested that most parents of autistic children had such thoughts at one time or another. Autism Hub promptly created an online petition entitled “Don't Speak for Us,” and many of the petition's signatories commented on the risk that the video and other similar depictions in the media might actually incite child murder.

The informal community of bloggers at Autism Hub had a significant impact in bringing disability rights issues surrounding autism into the public consciousness. Although well-funded organizations such as Autism Speaks largely dominated the discourse in 2006 and 2007 through traditional media, by this time society was becoming aware that other views existed. Autistic activists felt more empowered to assert themselves in the public sphere and to envision a future without the barriers created by ignorance.

Moving Toward Acceptance

The Autistic Self Advocacy Network (ASAN) was incorporated in November 2006 as a nonprofit organization run by and for autistics. Seeking to

address public policy issues relating to autism from a disability rights perspective and to teach self-advocacy and leadership skills, it began as a small, all-volunteer group that declared “Nothing About Us Without Us.” In December 2007, ASAN successfully organized an advocacy effort, together with Autism Hub’s bloggers, which brought about the removal of billboards in New York entitled “Ransom Notes” that had depicted autism and other disabilities as evil kidnappers snatching children.

I was invited to join ASAN’s board toward the end of 2008. During my first two years of service as an ASAN board member, it became apparent how quickly the culture was changing in the direction of acceptance. Pressure from autistic and cross-disability activists convinced Autism Speaks to disavow its September 2009 release of the video *I Am Autism*, which was another portrayal of autism as a child-snatching, family-destroying monster. The mainstream media and policymakers became more careful to use accurate and respectful language in referring to autism. President Obama appointed ASAN founder Ari Ne’eman to a term on the National Council on Disability that began in 2010.

I took down the original Autistic Genocide Clock page in July 2011 and posted a revised page [2] because I felt that autistic activism—including the efforts of Aspergia, AFF, Autism Hub, ASAN, and many others—had improved the culture enough so that routine prenatal testing for eugenics purposes would not be widely seen as desirable. Moreover, by then scientists had learned that the genetic factors involved in autism were very complex, which made it unlikely that any simple, routinely administered test would be developed. (Some tests do exist for single-gene conditions associated with autism, and this remains a concern to the extent they are used for prenatal testing rather than to confirm a clinical diagnosis.)

On the revised page, I wrote that although the cultural and political landscape had changed for the better in many ways since 2005, the history of that time period and the activists’ determined efforts should not be forgotten.

References

1. Herera, S. (2005, February 23). Autism research focuses on early intervention. *CNBC*. Retrieved from <http://www.nbcnews.com>.
2. Evans, M. (2011, July 16). *Autism research and prenatal testing*. Retrieved from <https://www.ventura33.com/clock>.

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