

Episode 4: The Spectrum 10k Controversy and A History of Eugenics

Hello again and welcome back to Actually Autistic Educator. So this episode originally was going to be wrapping up our three part series on autistic communication and focusing on autistic empathy, previous misunderstandings and new research, but some new things hit the autistic community this week that I think are important to cover, so our episode on autistic empathy will be pushed to next month, and this week we are going to examine the controversy around a new autism study launching called Spectrum 10K and why many autistics are concerned, and looking at this in the context of the history of eugenics against the disability community, both with autism and other disabilities.

First, this whole episode has a content warning for eugenics, offensive and outdated labels, Nazis, and poor treatment of autistics. I know normally I label and share specific time spots to skip, but after finishing my notes it's really the whole episode. If you are autistic and are already aware of all this and have been traumatized by how awful this week has been for autistics, seriously, feel free to skip this episode - our last mini one on famous autistics in popular culture is much less traumatizing, and the empathy one should be very validating next month - or as always full transcripts are given as links in the show notes and posted to my Twitter and Facebook for each episode if reading is easier than listening. As much as I enjoy seeing my number of plays go up, your mental health comes first; reading is always an option if it's better for any reason.

Additionally, as I decided to make this episode three days before it needed to go live, I do not have any interviews recorded with other autistics on this like my usual format, so sorry, I'm just going to be talking at you a bunch. I do have some great folks planned for next time though, promise, including my sibling

the autistic biology teacher!

A quick introduction to the Spectrum 10K project, they have announced the goal of getting the DNA of 10,000 autistics to create a database to examine the genetic and environmental causes of autism, to be able to identify different subgroups of autistics such as those with different other conditions like anxiety or ADHD, as well as different talents such as music. While they have stated they will not allow this to be used for eugenics for ways to create genetic testing in utero to eliminate autistics, many autistics have pointed out that 1) many of the researchers involved have direct ties to groups who have stated they wished to find a "cure" for autism through genetic testing, that 2) even if Spectrum didn't directly approve of a eugenics project, simply publishing the data of genes found to correlate to various autistic traits which are viewed negatively could allow others to create genetic testing from this data, and 3) that the focus on the genetic model takes money away from what could be spent actually supporting autistics through education and community support programs, and through teaching acceptance and accessibility, which is overwhelmingly what the autistic community has requested rather than additional genetic testing. We will be going into more detail in a bit, but you can check out the hashtags #StopSpectrum10K and #Spectrum10k to see the concerns being voiced by autistics and allies regarding both the project and the people involved.

Also, yes, I'm autistic, but I'm only one voice, and no community is a monolith. Check out the #ActuallyAutistic hashtag to see what the larger community is saying. Personally, I massively appreciate the works of a few folks on Twitter I want to credit who have shared great content, research, and their own thoughts and perspectives - these

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folks are great to follow in general and I will tag them in the Twitter post for this episode for ease of finding, or check page 2 of the transcript linked in the show notes. Huge thanks to Ann Memmott PGC @AnnMemmott, Emily @ItsEmilyKaty, Pete Wharmby @commaficionado, Sarah Boon @Saraheboon, and especially AutisticSciencePerson @AutSciPerson who has done extensive work on this and has been incredibly dedicated in advocating, researching, and sharing information on this and many other important autistic topics.

First, a recap of the history of eugenics around autism and other disabilities. As discussed in previous episodes, one of the earliest researchers to work explicitly with autistics was Hans Asperger, for whom the diagnosis Asperger was named after his work was eventually translated into English some 40 years later. While many people believed him to have been a supporter for autistics in that he identified children who were autistic, but he believed possessed various useful skills and “saved” them from the Nazis. However, the other side to that coin which has been proven in recent years is that the disabled children he did not think were talented he referred to the Nazi child euthanasia program where those viewed as a burden to society were “purified” from the gene pool. For citations and more details see our mini episode 2.5, The Problems with Functioning Labels.

This is part of a pattern of eugenics against various disability communities that is well documented. The article “Keeping the Backdoor to Eugenics Ajar?: Disability and the Future of Prenatal Screening,” a 2016 article, states that eugenics are “practices and policies designed to promote the reproduction of people with desired attributes—and, thus, avert the reproduction of people with undesired attributes (e.g., people with disabilities). The idea that the world and the people in it would be better off if everyone were born ‘healthy,’ that is, without ‘defect,’ is the essential principle of eugenics (translated literally as well-born). At the beginning of the twentieth century, eugenics emerged as an important ideology and

social movement in the US and beyond, reflected most profoundly not only in the institutionalization of certain people with disability (and other social groups) but also in policies of segregation and enforced sterilization programs. Whilst the word has dropped out of favor in the US, the actual practice of eugenics remained fairly consistent in US medical services over the decades both before and after Nazi Germany’s appropriation of eugenics for its own horrifying purposes.” I recommend doing even just some cursory internet searches on this topic if you are not already familiar with the US’s rarely acknowledged history of eugenics, which the Nazis directly were inspired by, including compulsory sterilization of an estimated 65,000 US citizens, and rulings such as this one from 1976 in North Carolina Association for [slur for intellectual disability] Children v. State of N.C. “The legislative dual purpose to prevent the birth of a defective child or the birth of a nondefective child that cannot be cared for by its parent reflects a compelling state interest.”

One of the most horrifying things in my mind currently done is a set of procedures called the Ashley Treatment, which even though this entire episode is one large content warning I am not going to detail here as I literally had nightmares about it after learning of it several years ago and this week has frankly already been traumatic enough for myself and fellow autistic and otherwise disabled or neurodiverse listeners, but for details and citations for all of these topics check out the 2012 article “Avoiding genetic genocide: understanding good intentions and eugenics in the complex dialogue between the medical and disability communities” published in Genetic Medicine.

Returning to “Keeping the Backdoor to Eugenics Ajar?” the paper expresses concerns regarding the current use of prenatal testing to identify Down Syndrome, which in some countries where the testing is highly encouraged for all pregnant people many reports show that approximately 95% or more of fetuses with Down Syndrome identified through prenatal testing are aborted, with the result that in all of Denmark in 2019

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only 18 were born with Down Syndrome. The 2011 article “Down syndrome: coercion and eugenics” shows “governmental rhetoric and policies condoning eugenics and commercial policies meeting criteria established by experts for eugenics,” something that many autistics have expressed concerns over - will parents be pressured by insurance companies into prenatal testing to avoid paying for services for autistic children and adults? A 2008 article titled “Informed consent or institutionalized eugenics? How the medical profession encourages abortion of fetuses with Down syndrome” points out issues of “societal pressures to have ‘normal’ children, a negative view of persons with disabilities by many in society, [and] a fear of legal liability by those in the medical community,” all of which could apply to any disabilities, including autism.

The 2012 article from Genetic Medicine recommended a few minutes ago describes the situation well, “the promise of genetic research is often described as the elimination of disabilities that occur naturally within the population. This leads disabled people to view the genetics revolution as one designed to prevent the birth of people like them. Scientists caught up in the excitement of genetic discoveries can forget that life with a disability can be rich and fulfilling. ‘Health’ is a subjective characterization, most often defined by health professionals, researchers, and the insurance industry, and not by people with disabilities.” Later it continues, very pertinently to the current debate, “The concern over genetic genocide is not misplaced paranoia on the part of the disability community. James Watson, the Nobel Prize-winning discoverer of the ‘double helix,’ has written that ‘seeing the bright side of being handicapped is like praising the virtues of extreme poverty.’ Like Charles Davenport, a leader in the early eugenics movement in the United States, Watson strongly supports the controlling of genetic destinies: ‘Working intelligently and wisely to see that good genes—not bad ones—dominate as many lives as possible is the truly moral way for us to proceed.’ Watson urges the scientific community to strive for human perfection because,

after all, ‘you always want the perfect girl.’” Yeah, there are many layers to how offensive all that is, and finally, “technological advances do not automatically translate into producing clinicians who understand, listen to, and value the needs and goals of their disabled patients.” Which really is a key part of this entire issue.

This history of eugenics has made this Spectrum 10k situation and the debates around other similar programs in the US very traumatizing for autistic advocates, but it is made worse as many of their supporters are telling autistics to their face that they do support this study because they explicitly want eugenics, while others accuse autistics of being anti-science or conspiracy theorists for raising this concern. I came across these statements on Twitter regarding Spectrum and creating prenatal testing, “research must be done so your harmful condition never happens again or gets reduced to near absolute zero.” Also “I think a better long-term solution for you and everyone else is ‘curing’ autism. So that you won’t become a burden towards yourself and society.” This is what I and many other autistic advocates get told on a regular basis. There is a sizable percentage of the population who are very open about looking for eugenics-based cures for autism, and the refusal to acknowledge these very real concerns is highly upsetting.

Sadly, there are even some autistics who, in the face of rampant societal ableism, have supported genetic research on the grounds that they want to be able to prove by a genetic test that they are one of the smart ones and not like other autistics to save themselves from ableism, which is utterly heartbreaking and horrifically offensive. To be clear, all autistics, and all people with disabilities, are deserving of life and joy. The internalized ableism is hard to work through sometimes, but the vast majority of autistic advocates do not ascribe to this theory and have repeatedly stated that they do not wish to be subdivided.

Let’s now take a look at some of the researchers and

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organizations involved in Spectrum 10k that autistics have raised concerns about.

A major player in autism research and one of the head researchers behind Spectrum 10K is Simon Baron-Cohen, and yes, he is in fact the cousin of the guy from the movie *Borat*. In the 90s, he wrote a lot about tying autism to gender, describing autism as “extreme male brain theory.” His evidence was to look at non-autistic women and men and have them take what he called an “empathy quotient test” often shortened to EQ, and then based on reported gender differences and comparing them to autistics, he wanted to see if autism was caused by testosterone. For all that the official definition of empathy here is about how well you can identify someone else’s emotional state, the actual questions of the EQ clearly also include how much you care about another person, which while the two may relate for some people, they can also be wildly different - you might care about me as a human and still not be able to interpret the way my head tilts when I’m frustrated, but by including statements such as “I really enjoy caring for other people” and using them for a linear scale of empathy along with statements like “If anyone asked me if I liked their haircut, I would reply truthfully, even if I didn’t like it” you can see how non-autistics didn’t actually distinguish between our emotional state of caring or not vs our communication preferences of more authentic communication, but rather made broad generalizations based on their own perspective. We’ll be looking at this in more detail in next month’s episode on autistic empathy.

Beyond the frustrating misuse of the word empathy, which has been used to stereotype autistics as non-caring and therefore as justification for our murder and abuse by caregivers, Baron-Cohen shows his tendency to look exclusively for genetic causes of differences rather than acknowledging social ones - it is incredibly sexist to assume the gendered results between men and women’s empathy quotient answers are due all to testosterone and not the massive amount of social pressure placed on people

presumed female from a young age to be hyper aware of others’ emotions and to value the comfort of others over their own. To be clear, this is bad and we need to stop forcing young people into these gender roles, especially when it tells girls the most important thing they can be is someone who serves others at the expense of their own mental health, but this just shows the pattern of many non-autistic researchers of autism to focus on genetics when the actual problem is society, both sexism and ableism.

And to be clear, there are many even more concerning comments from Baron-Cohen about gender, including this one, “on the SAT-Math test, the sex ratio at the 99th percentile is 2:1 (m:f). This difference is likely to reflect genetic or prenatal steroid hormonal factors. Among all Fields Medal winners (the equivalent of the Nobel Prize in mathematics), 54 out of 55 have been male.” This is horrifically sexist and using the trappings of science to argue that men are just inherently better at math because of testosterone rather than think that maybe societal sexism impacted who was given math awards is why autistics point out that it’s not anti-science to question the results of data that are impacted by social pressures and under the control of people who have serious biases. And to be clear, I didn’t dig that up from the 80s or 90s, that was from “Autism, maths, and sex: the special triangle” published in 2015. I could list numerous more quotes from Baron-Cohen showing a prolonged history of offensive statements regarding both sexism and the condescension in how he refers to autistics, including his arguments that we should still split out the talented autistics as Aspergers rather than grouping them under autism - which as a reminder, this subgrouping was first created so that the “lower functioning” autistics would to be murdered by Nazis, so none of this should really still be being pushed, especially as the majority of autistics directly reject the idea of dividing us.

Recently going around on social media has been a quote from a 2009 interview of Baron-Cohen with the BBC titled “Autism test ‘could hit maths skills.’”

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Speaking about genetic testing he says, “If it was used to ‘prevent’ autism, with doctors advising mothers to consider termination of the pregnancy if their baby tested ‘positive’, what else would be lost in reducing the number of children born with autism? Would we also reduce the number of future great mathematicians, for example?” He continues “Caution is needed before scientists embrace prenatal testing so that we do not inadvertently repeat the history of eugenics or inadvertently ‘cure’ not just autism but the associated talents that are not in need of treatment.” Many autistics have noted that his only objection to autistic eugenics in his writing and interviews seems to be that if we remove autistics we might have fewer mathematicians or other great skilled individuals who he doesn’t want to lose by mistake, but he seems to not be concerned about the actual issue of eugenics when applied to the people who aren’t brilliant mathematicians, musicians, or scientists, and in fact in other interviews for Spectrum he stated that he is looking for genetic markers to identify both skilled mathematicians and musicians, presumably with the goal to make sure we don’t lose them as that is the only value he sees in autistic lives. One activist I spoke to pointed out similarities to Hans Asperger, saying both are men lauded as a supporter of autistics because they uplift and validate specific autistics based on their skills, but lack regard for the wellbeing of autistics who aren’t “useful,” who are free to be eliminated. Unsurprisingly, given this history this is a major concern by many autistics and allies regarding his involvement as a leader and spokesman for the Spectrum 10k project.

Simon Baron-Cohen’s history of disregarding the social elements of human behaviors and insisting all are genetic is seen with his plans in the Spectrum 10K study to identify why certain autistics are more prone to things like anxiety by looking at genetics, despite the fact that as we discussed last episode, multiple studies, including one with his name attached, have confirmed the link between masking, which is caused by social pressures, to anxiety. This is

why autistic self-advocates have asked repeatedly for funding education to retrain professionals to a more accurate understanding of autism, for additional supports for adult autistics to let them live and work in their own communities, and for more research into how ableism is impacting us and how we can create a more inclusive and supportive environment for autistics, rather than yet another genetics study.

He is not the only major researcher attached to the program though, a co-leader is Daniel Geschwind, another well-known non-autistic researcher of autism, whose past projects include “Cure Autism Now” which has a clearly stated goal in the title, and was incorporated with Autism Speaks, which most autistics consider a hate-group. In his profile in Spectrum News from 2009, he describes his thoughts on autistics, saying “If you’re interested, even in a more abstract way, in human behavior and human cognition, autism is an extraordinary window into that,” “It involves dysfunction in social cognition, language – the things that are really part of what makes us human,” which sounds concerningly like dehumanization of autistics. He is another man who sees the biases in autistic diagnosis as being clear proof that autism is tied to sex, to the extent that in 2004 for a study titled “Evidence for sex-specific risk alleles in autism spectrum disorder.” Geschwind’s team removed girls with autism from linkage study samples and used them as a comparison to boys, repeating many of the same sorts of things said already today regarding autism as a male disorder, but which yet again is making broad conclusions based on potentially very flawed data - the diagnostic criteria used to assess these people initially and decide if they were autistic or not are by no means infallible, and in fact have been critiqued extensively due to the fact that the criteria were created by non-autistics looking at predominantly white cis boys from certain income groups. This is a serious issue many autistics have brought up - if this study finds some genetic connection that is based on the existing very racially and gender biased diagnostic tools, then how long will it take for insurance companies to argue that

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because a woman lacks the genetic marker decided on by looking only at cis men that she therefore isn't autistic and services will not be covered, or accommodations for work will be refused without positive test results? Without vastly more autistic researchers to be able to call out and recognize the serious flaws in the field of autism studies caused by generations of only looking at it from the outside, the autistic community's concerns here seem incredibly valid, and specifically not just white cis male autistics, we need trans autistics, autistics of color, and autistic women to be given space to examine the societal barriers to accurate diagnoses. For more sources and interviews on this topic check out episode 1 of this podcast, *Rejecting the Blue*, issues of sexism and racism in autism research.

There are also concerns regarding one of the sponsors, the Wellcome Sanger Institute. In recent years there have been controversies regarding bribery, misuse of DNA in genetics projects (which is rather concerning) and holding stake in companies producing treatments they advocated for without listing a conflict of interest. This was not deep journalism on my part by the way, after seeing several people mention it, I just did an internet search for the name and "controversy" and a concerning number of articles just from the last few years showed up.

Regarding Spectrum 10k's marketing, there also seems to be a serious disconnect between many of the statements on the website that directly state that they do not plan to use this data for eugenics when compared to what is being said in their academic papers and grants, as well as in interviews, which has made many autistics feel they are being condescended or lied to and manipulated. The Autism Research Centre with the University of Cambridge is sponsoring the study, but on their website you see language like "Genetic research can also aid 'stratification' of autism into subgroups." Likewise, the grant application from 2018 for the project titled "Common Variant Genetics of Autism and Autistic Traits (GWAS) Consortium" states that "We will

accelerate gene discovery by collecting DNA samples from 10,000 people with autism in the UK and their immediate families. We will combine this information with genetic information from 90,000 other people with autism already gathered from around the world. This large-scale resource will enable us to identify several genetic variants that contribute to the development of autism. This information will allow us to better understand the biology of autism, improve on existing methods for diagnosing autism and investigate if there are genetically-defined subgroups of people with autism." There are multiple concerning things here. The fact that the Spectrum 10k website makes no mention of combining people's data into an even larger pool, while explicitly looking for ways to split autistics into subgroups, which, as we have mentioned already, is very problematic and usually based on how "productive" a member of society they think us to be, is incredibly concerning. Many autistics using the #StopSpectrum10k hashtag have said it looks like these researchers are trying to claim to support the autistic community and to avoid their well-cited concerns given many of the researchers' direct connections to previous attempts to find cures and other harmful goals, by purposefully misleading us about the purposes of the project.

Watching the hashtags *ActuallyAutistic* and *Spectrum10k*, you see a lot of other concerns being raised as well, such as the fact that Spectrum 10k encouraged parents of autistic children to sign their children up to give their genes and medical history away despite the fact that these kids can't consent, and there have been seriously concerning things said to autistics by some of the official brand ambassadors, including "You have a degree in genetics from the University of Brainless Ideologues, I see. Congratulations." To be clear, this is from someone who is listed on Spectrum's website as an official brand ambassador, in the course of advocating for the study. I reached out to Spectrum 10k via Twitter regarding this tweet on August 24th and as of August 30th I have not received a reply, or seen any apology given by Spectrum for her inflammatory and directly

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insulting attacks on multiple autistics, and she is still listed on their website as a brand ambassador.

Multiple autistics with large social media presences have also stated that they were approached to be a brand ambassador, but when they raised concerns and wanted to be more than just used as propaganda, they stopped getting replies. Baron-Cohen has stated that there will be some autistics on a decision-making panel for which projects can use the data, but the fact that the only autistics listed on the website are some of the brand ambassadors and none of the researchers, despite the fact that there are numerous autistic researchers of autism available, is seen by the autistic community as further proof that autistics are not actually being listened to. The list of concerns by autistics is very long and given the real risks to the community of this study, it is concerning that none of the primary researchers or decision makers were autistic, and yet when these concerns are raised autistics are being ignored or told they lack the comprehension to see that non-autistics know better about what we really need to improve our quality of life.

So, was all of this controversy inevitable? How can it be avoided in the future by groups wishing to do research into autism and have the support of the autistic community?

It's actually quite simple but requires non-autistics in positions of power to accept that they are not the people who should have the control. If you are not autistic and want to help, hire autistic researchers, uplift diverse autistic voices, cite articles by autistic scholars, hand over control to autistic scientists, and listen to what actual autistics from a variety of backgrounds are asking for. That's really all there is to it. The problem is that this requires people with privilege to acknowledge that they don't actually know better than us what we need, and sadly ableism is deeply entrenched in academia. As long as non-autistics insist that they should ultimately be the

ones in control of the narrative around autism the greater autistic community will rightly be concerned that their wellbeing, perspectives, and goals will be ignored and will not want to support these initiatives. A person on twitter recently suggested updating the disability motto from Nothing About Us Without Us to Nothing About Us Without Us Leading. I really like that, and I hope you do too.

Thank you for joining me for this special episode of Actually Autistic Educator, updating with main episodes the first of each month with mini-episodes in-between. I haven't decided what but our next mini-episode will definitely be on something less traumatic, and join me next month for our previously planned full episode on autistic empathy, misunderstandings in research and the double empathy perspective.

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