

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

Overview

This week a new project was announced in the UK called Spectrum 10k, with the goal to collect the DNA of 10,000 autistics for various research purposes. It is supported by several big names in autism research, but numerous autistics have raised serious concerns regarding the use of genetic testing to eliminate or cure autism, as well as regarding several of the researchers and groups associated with the project. This has resulted with #ActuallyAutistic and #StopSpectrum10k going viral as the autistic community has pushed back against this internationally. This episode details many of the concerns raised by autistics regarding the research and people involved, as well as looking into the history of eugenics against the disabled in the last century and currently occurring even today. Finally, we look at some ways to avoid these outcomes by creating more inclusive research teams and being willing to examine privilege and power dynamics present in academia.

Key Points:

- There is a long history of eugenics in disability and autistic history, including Hans Asperger who divided autistics and sent those seen as “low functioning” to Nazi child euthanasia camps, the forced sterilization of people with disabilities, and dramatic reductions in birth rates in certain disability communities after pre-natal genetic testing was made available. This understandably gives many autistics serious concerns about the safety of future autistics if genetic studies pinpoint the markers of autism.
- Several researchers and organizations associated with the project have a history of concerning statements, both in regard to autism and other

societal issues such as sexism. The focus on genetic elements for comorbid conditions clashes with much current research that has connected depression and anxiety in autistics to social pressures, rather than to genetics.

- In order to actually best serve the needs of autistics, and to create buy-in from the autistic community for these sorts of projects, autistics need to be given positions of authority and control from the ground up in research projects focused on autism, not merely brought in for token positions after major decisions are made.
- Time: 33:12

Quotes:

“This history of eugenics has made the 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... 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.”

“‘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’ (Simon Baron-Cohen, 2015). This interpretation is horrifically sexist and using the trappings of science

Actually Autistic Educator

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to argue that men are inherently better at math because of testosterone rather than consider that societal sexism may have 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."

"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."

"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 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?"

"We need trans autistics, autistics of color, and autistic women to be given space to examine the societal barriers to accurate diagnoses."

"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."

Articles referenced:

Keeping the Backdoor to Eugenics Ajar?: Disability and the Future of Prenatal Screening. Gareth M. Thomas, PhD and Barbara Katz Rothman, PhD. AMA J Ethics. 2016;18(4):406-415. doi: 10.1001/journalofethics.2016.18.4.stas1-1604.

Miller, P., Levine, R. Avoiding genetic genocide: understanding good intentions and eugenics in the complex dialogue between the medical and disability communities. Genet Med 15, 95–102 (2013). <https://doi.org/10.1038/gim.2012.102>

"Autism, maths, and sex: the special triangle" Simon Baron-Cohen, Published: September, 2015 DOI: [https://doi.org/10.1016/S2215-0366\(15\)00397-1](https://doi.org/10.1016/S2215-0366(15)00397-1)

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