

# ASAN Statement on Genetic Research and Autism

## Concerns

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### *Genetic research has big risks and big benefits*

#### Risks of genetic research

##### Research into cures

Scientists have developed technology that allows them to edit genes. If a scientist edits a person's genes, they might be able to change something about that person. For example, some people have a blood disease because of a gene they have. If a scientist edits the gene that causes the blood disease in someone, that person might make new blood that does not have the disease. Eventually, the person would not have the blood disease anymore.

This kind of gene editing does not happen very much right now. But it could happen more in the future.

ASAN is against ever using this kind of gene editing for autism. We think it would be used to treat or "cure" autism. We do not want "cures" for autism. We want to continue being autistic.

ASAN is concerned with research into potential genetic "cures" for autism. There are three types of potential genetic "cures" we are worried about. The first are genetic "cures" before a child is born, or "in utero cures." These would involve editing the genes of a fetus when it is still growing inside its parent's body.

The second kind of genetic “cure” happens after the person is born. It would involve editing the genes inside the person’s body. It would probably involve editing the genes in someone’s brain.

The third kind of genetic “cure” would involve germline gene editing. Some scientists are researching how to change a gene in ways that can be passed down to a person’s children. This is called “germline” gene editing. If you changed the genes this way, an autistic person’s children would not be autistic.

ASAN does not want a “cure” for autism. We do not want any research that could come up with a “cure” for autism. Part of why we are worried about autism genetic research is that there are not enough rules to keep people from doing genetic research to find a “cure” for autism. We want there to be more rules about genetic research. We want there to be rules saying people can’t use genetic research to find a “cure” for autism.

We are also worried that if scientists tried to “cure” an autistic person using genetics, that could cause more problems for the person. The genetics of autism are very complicated. We know there are lots of genes that cause autism. We know that the genes that cause autism can cause other disabilities, like ADHD and schizophrenia.<sup>1</sup> ASAN is worried that changing the genes that cause autism could cause autistic people to have other disabilities. We are worried that it could hurt autistic people in ways we don’t know about.

## Prenatal testing

Prenatal testing is genetic testing to see if a fetus has certain disabilities before the fetus is born. For example, there is a prenatal test for Down Syndrome. This test says it can tell pregnant people whether their fetus will have Down Syndrome before the fetus is born.

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<sup>1</sup> Thapar, A. (2018). Discoveries on the Genetics of ADHD in the 21st Century: New Findings and Their Implications. *American Journal of Psychiatry*, 175(10), 943–950. <https://doi.org/10.1176/appi.ajp.2018.18040383>

There are problems with prenatal testing. For example, tests for rare conditions (where only 1 in 5,000 people have the condition), are wrong about 8 out of 10 times.<sup>2</sup> Autism is not rare. But the genetics that might cause autism are very complicated. ASAN is worried that a prenatal test for autism might be wrong a lot of the time.

But even if a prenatal test for autism was correct most of the time, we are still worried about prenatal testing. Lots of prenatal tests portray disability as “unhealthy” and something parents do not want their child to have.<sup>3</sup>

We support the legal right of any person to have an abortion for any reason. Every pregnant person should be able to choose whether to have a child or not. People should be able to choose without anyone or anything forcing or pressuring them. We also know that we live in a very ableist society, in a country where people with disabilities and our families do not get the support we need. We are worried that this ableism and lack of support are ways society uses force when people are thinking about whether or not to have an abortion.

Instead of prenatal testing, we want to get rid of ableism. And we want to see better support for people with disabilities and our families.

## Equity concerns

There are equity (fairness) problems when new health technologies, like gene editing, are introduced. Often, insurance does not cover new health technologies. People have to pay for them on their own. So, only rich people can pay for them. People of color and people with disabilities are more likely to be low-income. So, they have much less access to new health technology.

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2 Kliff, S., & Bhatia, A. (2022, January 1). When They Warn of Rare Disorders, These Prenatal Tests Are Usually Wrong. *The New York Times*. <https://www.nytimes.com/2022/01/01/upshot/pregnancy-birth-genetic-testing.html>

3 Meredith, S. (2022, February 2). In Response to the NY Times: Prenatal Screening and the Social Bias Against Disability. *Center for Dignity in Healthcare for People with Disabilities*. <https://centerfordignity.com/prenatal-screening-and-social-bias/>

Also, once health technologies like prenatal testing and gene editing become common and cheaper, there is a risk that they'll be used with force on lower-income people, especially people of color. For example, women of color, including Black women and Native American women, were targeted for forced sterilization at many times in the U.S.' history. Forced sterilization means being forced to have an operation that makes it so someone cannot have children.

Prenatal testing or gene editing could also be forced on people. For example, someone could have a child with a genetic disability. The child's disability could have been prevented through prenatal testing or gene editing. When the parent applies for Medicaid for their child, the government says their child cannot get Medicaid because their disability was "preventable." This policy would force people to use prenatal testing or gene editing. This policy is not happening right now. But, advocates are worried that it could.

ASAN also wants to make sure that genetic testing isn't used as a way to keep people from getting services. For example, we would not want someone to have to "prove" they are autistic through genetic testing in order to access Medicaid services. This is also an equity issue. We have already addressed that genetic testing for autism, if developed, will probably be very expensive. If people had to get genetic testing in order to qualify for services, that would mean people who couldn't afford the testing couldn't get services. People who couldn't see a doctor who could perform the testing then couldn't get services. ASAN believes all disabled people should be able to access the services they need. We worry that service providers would use genetic testing to say that people can't get services.

ASAN worries about all of these things happening because of genetic research around autism. We don't want genetic testing or treatments related to autism to create more inequality or to be forced on people.

## Privacy concerns

Privacy is the right to keep your personal information a secret. Everyone has the right to privacy. All people with disabilities have the right to privacy.

Your genes determine a lot of things about you. Some of these things can be very personal things people might want to keep private. For example, some genes can cause a person to be at very high risk for types of cancer. A person with those genes might not want other people knowing they are at very high risk for cancer.

ASAN is worried about how the information from genetic testing will be kept private. We want people with disabilities to have the final say about who gets this information. We don't want just anyone to have access to this information. We are worried about what might happen if other people find out about the results of someone's genetic testing.

For example, a person with a disability under guardianship might have genetic testing done. The genetic testing says that they have a disability they could pass on to their children. The person's guardian finds out about the testing result. Then, the guardian uses the result to say that the person shouldn't be allowed to have children.

There are problems with genetic research being available to everyone. If everyone could see all genetic data on autism all the time, someone might try to use it to prevent autistic people from being born. Some genetic data might have personal information associated with it, like names or birthdays, which can be used to discriminate against people.

There are some laws in the United States that protect privacy in health care and genetic testing specifically. However, these laws do not cover everything. For example, it is illegal to deny someone health insurance because of the results of their genetic testing. But it is still legal to deny them *life* insurance because of the results of their genetic testing.<sup>4</sup> ASAN

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4 Peikoff, K. (2014, April 7). Fearing Punishment for Bad Genes. *The New York Times*. <https://www.nytimes.com/2014/04/08/science/fearing-punishment-for-bad-genes.html>

thinks there need to be more protections against discrimination based on genetic testing.

Companies that do genetic testing usually keep a record of the genetic testing they do. There are a lot of different groups that might want access to that genetic information, such as different researchers, big companies, health care organizations, and the government. We don't know what each of these groups would do with the information. We don't know if they would do good or bad things with it. We worry about what the companies that have the information will do with it, like whether they will sell it to another company. We think there should be more rules about how companies can use the genetic information they get from genetic testing.

## Who is in control of this research

A lot of people get genetic testing for lots of different reasons. Much of the information from that testing goes into databases. A database is like a bank for genetic information. Databases store huge amounts of genetic information.

ASAN worries about who will control genetic information about autistic people. We know that there are already databases that store large amounts of autistic genetic information. We do not want these databases to be controlled by people who might want to do eugenics or get rid of autistic people. We also know that the more people who have access to these databases, the more likely it is that someone will try to use the information for eugenics.

It may be useful to look at genes collected from lots of autistic people. Researchers could use the data to look at how co-occurring conditions (for example, disabilities that cause seizures) work in big groups of autistic people. Researchers could use it to see whether autistic people have similar genes.

But it is also very risky to look at genes collected from lots of autistic people. There is no way to predict how data on the genes of a large number of autistic people will be used. Even if the data collectors have good intentions, sharing of the data will make it very likely that someone will use it to try to “cure” or prevent autism. For example, if autistic people do have genes in common, the data might be used to detect autism in fetuses before they’re born.

Creating a list of autistic people may have other bad consequences. The list might allow for disability discrimination if the data privacy isn’t carefully monitored. For example, Britain’s largest sperm bank tried to ban autistic people from donating sperm.<sup>5</sup> Other types of unfair treatment could occur too, such as organ transplant discrimination or discrimination in emergency medical treatment at hospitals.

ASAN is concerned about equity in how autistic people’s bodily samples are used. Part of saying “yes” to genetic research is that you know *all* the different ways the research and any bodily samples you give could be used. We worry that people’s samples could be used in ways they didn’t say “yes” to.

One example of this from history is the case of Henrietta Lacks. Henrietta Lacks was a Black woman who had cancer. Some of her cells were taken from her body to do a test for cancer. The cells were later grown into more cells to do other research on. Henrietta Lacks’ cells are still being used to do research today. But neither Henrietta Lacks nor any of her family members gave consent for her cells to be used for research. People today still debate whether Henrietta Lacks’ cells (called *HeLa cells*) should be used for research.

We are worried that samples taken from autistic people (like cells) could be used to do similar things. We are worried autistic people wouldn’t

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<sup>5</sup> Cha, A. E. (2019, October 3). Danielle Rizzo’s donor-conceived sons both have autism. Should someone be held responsible? *Washington Post*. <https://www.washingtonpost.com/health/2019/10/03/danielle-rizzos-sons-donor-conceived-sons-both-have-autism-should-someone-be-held-responsible/>

be given the information we need to consent to research being done on our cells. We are worried genetic research would be done on our cells without our consent. We are especially worried this would happen to autistic people who face other kinds of unfair medical treatment, like autistic people of color, autistic women, autistic transgender and non-binary people, autistic children, autistic people with intellectual disabilities, and non-speaking autistic people.

## **These concerns apply to all autistic people**

Some people say that genetic testing and treatment will only be used for autistic people with high support needs. Even if that were true, ASAN would still be concerned. We do not believe that any autistic person needs to be “cured.” This includes autistic people with the highest support needs. Autistic people with the highest support needs are some of the most vulnerable members of our community. They deserve good lives with the right to make their own decisions, not yet another round of “cures” that will not work.

## **Autism and genetics are really complicated**

Genes can control multiple things in your body. A gene that might cause autism might also control other things that are important in someone’s body. For example, the same gene might change how your brain works, and also how you digest food.

There are many different genes that might cause autism. We don’t know which genes exactly cause autism, but we know that it’s not just one gene. Sometimes, these genes are the same genes that cause other disabilities, like ADHD or schizophrenia. Researchers don’t know how to predict which disability will happen.

Because there are lots of different genes that might cause autism, and because those genes might also cause different disabilities, figuring out how to make a genetic test for autism is very complicated. Researchers

have spent a lot of time trying to figure this out. One type of testing that could be used for autism is polygenic screening. Polygenic screening looks for changes in multiple different genes to tell what the chance is that an embryo might have a certain health condition. Polygenic screening can look for different disabilities, like heart disease or certain mental health disabilities. Polygenic screening cannot diagnose conditions for certain. It can only say how likely it is that an embryo might have a certain condition.

Right now, polygenic screening is only done in embryos. But scientists are doing research to develop polygenic prenatal testing that could eventually be used on fetuses. ASAN is worried polygenic screening could be used to identify embryos that might be autistic.<sup>6</sup> We are also worried that polygenic screening could be used to identify embryos that might have co-occurring conditions, like intellectual disability. We have the same concerns about polygenic screening that we have about prenatal testing.

## Genetic research probably won't work like some people think it will

Some people think genetic research and editing is like flipping a light switch. They think that flipping the switch will cause the genes to “turn on” or “off” and the problem will immediately be fixed. This is not true. Genetic editing is really complicated. Most genetic disabilities are caused by multiple genes. And, some genes do multiple things. We don't know what would happen if someone tried to “turn off” the genes that caused a disability. We also don't know exactly which genes control many disabilities. So it is not as simple as just “turning off” or “on” certain genes.

We don't know the long-term effects of “turning off” autism genes. “Turning off” those genes could lead to other disabilities and illnesses

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<sup>6</sup> Shanks, P. (2021, September 30). *The First Polygenic Risk Score Baby*. Center for Genetics and Society. <https://www.geneticsandsociety.org/biopolitical-times/first-polygenic-risk-score-baby>

later in someone's life. In one test, scientists tried to edit genes to cure a form of blindness. But the test didn't work, and the cells the scientists tested ended up losing big chunks of their genetic information.<sup>7</sup>

## Even if it doesn't work, it's still dangerous

Even if autism genetic research can't be used as a "cure" for autism, it's still dangerous.

As we have said already, there are plenty of fake "treatments" or "cures" for autism that do not work but people try them anyway (for example: chelation, bleach, restrictive diets). We are worried that the same people who promote these "cures" for autism will target the families of people whose genetic tests show they may have autism. We are also worried about fake "genetic cures" for autism that are potentially even more dangerous than the fake "cures" we have already.

We already know that even if there are not "official" genetic tests for autism, people try to do it themselves. There are already genetic testing kits people can buy that say they can screen for lots of different genes, including genes that cause autism. There are also kits that say they are meant for people who have already been diagnosed with autism<sup>8</sup>. These kits say that they are not meant for people to try and diagnose autism through genetic testing. But some people will use the kits to try and diagnose autism anyway.

There are already ways people try to use genes to make sure their children won't be autistic. One example is that families who already have autistic children are told to only have girls if they have more children. (There are genetic tests that tell if a fetus will be assigned female at birth before it is born.) This is based on the belief that girls are less likely to have autism than boys. This "advice" is not recommended by any official

<sup>7</sup> Marchione, M. (2020, October 29). Lab tests show risks of using CRISPR gene editing on embryos. *STAT*. <https://www.stat-news.com/2020/10/29/lab-tests-show-risks-of-using-crispr-gene-editing-on-embryos/>

<sup>8</sup> For example, Genetic testing for autism. (n.d.). *Blueprint Genetics*. Retrieved March 22, 2022, from <https://blueprintgenetics.com/tests/panels/neurology/autism-spectrum-disorders-panel/>

group of doctors or scientists. But some doctors still recommend it to patients.

Another way people try to stop autistic children from being born is to stop autistic people from donating sperm or eggs. Sperm or egg banks (where people can donate their sperm or eggs so other people can use it to have children) will sometimes say autistic people can't donate their sperm or eggs. This is to "prevent" children that come from those sperm or eggs from being autistic. This is ableist. This is eugenics. It is not right to prevent someone from donating their sperm or eggs because they are autistic. But it still happens.

We are also worried about people being advised not to have children because they have a gene that could cause autism. For example, some neurotypical siblings of autistic people aren't autistic, but have the same genes that could cause autism. We don't know why this happens yet. But a genetic counselor might tell them not to have children, because their children might be autistic. In this example, what the genetic counselor did is a form of eugenics. Trying to prevent people with "autism genes" from having children is eugenics.

Finally, genetic research takes time and money away from other kinds of research that would probably help autistic people more. A lot of kinds of autism research don't get that much money at all. For example, research into what services would help autistic people the most doesn't get much money, so not many scientists do that kind of research. We want more money to go towards research into how to help autistic people in our everyday lives, not to genetic "cures" research.

## Potential benefits of genetic research

### Treating other conditions that autistic people often have

One possible benefit to genetic research is finding causes and possible treatments for other disabilities that autistic people often have, like seizures or stomach issues. These disabilities are called “co-occurring conditions.” A lot of autistic people who also have these disabilities or medical conditions don’t want to have them. They still want to be autistic, but they don’t want to have the other disabilities or medical conditions.

Looking into the genes behind these co-occurring conditions could help us treat the co-occurring conditions. If a doctor knew exactly what genes someone had, that might help the doctor know which medications would or wouldn’t work for that person. This would mean autistic people could get better health care for our co-occurring conditions.

Gene editing, if possible, could also help cure some of these co-occurring conditions. For example, some autistic people also have co-occurring conditions that cause seizures. If genetic editing worked well enough, scientists could edit the genes in these people’s brains so that the people wouldn’t have seizures anymore. That would be a genetic cure for their seizures.

No matter what, autistic people need to be in charge of decisions about our health care. Even if genetic research could help treat co-occurring conditions, not all autistic people want to treat their co-occurring conditions. Not all autistic people want to use genetic research to look for, treat, or cure co-occurring conditions. Genetic research might get a lot better and safer, but that doesn’t mean all autistic people will want it.

Also, treating or curing co-occurring conditions is not the same as treating or curing autism. While some (but not all) autistic people will want treatments for their co-occurring conditions, most autistic people

don't want cures for autism. Testing and treatments for co-occurring conditions need to be very clear that they are not the same thing as testing and treatment for autism.

## **Some autistic people may want to know more about their genes**

Some autistic people may want to know more about their genes. People undergo genetic testing for many different reasons. We support autistic people who want to know more about their own genes, or the relationship between autism and genetics in general.