

# ASAN Statement on Genetic Research and Autism

## Background

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### *Autism Research*

#### **What is research?**

Research is the process of trying to answer a question or find the solution to a problem. Scientists do research on many different questions or problems. For example, scientists might research how to cure a certain type of cancer. There are many different ways scientists do research. We will talk about some of those ways later on in this statement.

#### **What is autism research?**

Autism research is research about autism and autistic people. It is the process of trying to answer questions about autism and autistic people. Here are some questions that autism research might try to answer:

- How do we help autistic people live better lives?
- Why do autistic people sometimes have trouble making friends?
- Why can some autistic people speak but other autistic people can't?
- How can we help autistic people get better health care?

## What does ASAN think about autism research?

ASAN thinks autism research should help autistic people. Scientists who do autism research should listen to autistic people. Scientists should work with us to make sure we are okay with the research they want to do.

ASAN thinks that more scientists should do community-based participatory research, or CBPR. CBPR is a kind of research where members of the community help make the research projects that are about us. Researchers and the autistic community can work together to help make our lives better. To learn more about CBPR, you can visit the website of the Academic Autistic Spectrum Partnership in Research and Education (AASPIRE, <http://aaspire.org>), which ASAN is proud to be a part of.

ASAN is against any research that tries to find a cure for autism. We don't think that autism can be cured. We don't think that autism should be cured. Most self-advocates agree that autism doesn't need to be cured. Instead of wasting time and money on something that isn't possible and that autistic people don't want, we should focus on supporting autistic people to live good lives.

### *Genetic research*

#### What are genes?

Genes are instructions inside your body that explain how you are made. They control a lot of things about you, like how your muscles work or what color your eyes are. Scientists think that some genes determine whether you are autistic or not.

## What is genetic research?

Genetic research is research about genes. There are many different kinds of genetic research. There is research on different genes, and there are different ways of doing genetic research.

Genetic research has many uses outside of humans. For example, we can use genetic research to grow foods that are bigger and tastier.

## Genetic research, eugenics, and medical racism

We have known about genes since the mid-1800s. Most genetic research has taken place since the mid-1900s. There are many different kinds of genetic research.

Soon after we learned about genes, people started connecting genes to their racist, ableist ideas. They called these ideas “eugenics.” Eugenics is the idea that some people have “good genes” and some people have “bad genes.” People who support eugenics think that people they believe have “good genes” should have lots of children. They want to reduce or get rid of groups of people that they think have “bad genes” by making sure those groups don’t have children. People who believe in eugenics think that disabled people are worth less. People who believe in eugenics also think that people of color are worth less. Eugenics is always wrong. ASAN is against eugenics.

Scientists should never use genetic research for eugenics. It is important to disabled people and other marginalized people that scientists never use genetic research for eugenics.

People have also used genetics and eugenics to say that medical racism is okay. Medical racism is when people of color get worse health care than white people. Medical racism is wrong. ASAN is against medical racism.

## Genetic research and a “cure” for autism

ASAN thinks that finding a “cure” for autism is bad and probably impossible. But a lot of non-autistic people believe that finding a “cure” for autism is a good thing. Scientists have been trying to find a “cure” for autism for a long time. A lot of scientists and doctors pretend that they can “cure” autism. They use things like medications, chelation, bleach, restrictive diets, and other things that don’t work and can actively harm autistic people. They convince families to give them money in order to hurt disabled children. ASAN thinks this is wrong.

Autism is a genetic disability. This means that genes cause autism. A lot of scientists and doctors are still trying to find a “cure” for autism. Now, some of them are using genetic research. They think that if they can “turn off” the genes that cause autism, they can “cure” autism. ASAN is against this. We will talk more about genetic “cures” for autism in a later section.

Even though we know autism is a genetic disability, we don’t know exactly which genes cause autism. There are over 20,000 genes in humans. We think that autism is caused by many genes, not just one. A lot of scientists and doctors are looking at which genes might cause autism. ASAN is concerned about this. We think this “cause research” is just another kind of “cure” research. We think that if doctors and scientists find a cause for autism, they will try to use it to create a “cure” for autism.

ASAN does not think autism is a good or bad thing. We think it is just another way to be a person. People who want to “cure” autism think autism is a bad thing. They want autism to go away. Because they think autism is bad, they think it is bad to be autistic. ASAN thinks these people are wrong. We want them to see autism as just another way of being a person.

# 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.

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.

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1 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>

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>

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.

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.

<sup>3</sup> 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/>



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 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

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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>

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 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.

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5 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/>

## 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 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.

6 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>

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

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 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

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8 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/>



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.

# Recommendations

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## *We believe safeguards are needed for all genetic research relating to autism*

There are reasons why autistic people might want to take part in autism genetic research. ASAN is not opposed to these reasons. However, we know that there is a potential for a lot to go wrong with autism genetic research. There is a potential for a lot of people to get hurt by autism genetic research. So we think there should be safeguards in place before autism genetic research can happen. Safeguards are rules that autism genetic research scientists have to follow. They are rules that help keep autistic people and our genetic information safe.

## *Safeguards*

### Privacy and consent

Genetic research means taking people's genetic information. This happens by taking samples from people's bodies, like spit or blood samples. When people take part in genetic research, they give samples from their bodies to be studied. The people who give samples are called research participants.

Collecting people's genetic information is a privacy issue. Autistic people who take part in research, like everyone else, have a right to privacy. We have a right to not have our genetic information shared without our permission. **ASAN believes that there need to be more protections on how people's genetic data is shared.** We believe that privacy should be the default, not the exception.

**ASAN supports rules to limit who can see and use genetic data.** We support rules that make sure only the researchers themselves can see and use the data. If the researchers want to share the data with other

researchers, they should have to get permission from the research participants first. Research participants should get to control our own data. This means we should decide *who* can use our genetic samples and data. We should get to decide *how* people use our genetic samples and data.

**Families and guardians should not be able to agree to share the data on behalf of autistic adults.** Autistic adults ourselves should have to agree to share it.

**ASAN wants to see research into more and better ways for people to give informed consent.** Informed consent is when someone is given all the information they need to make a decision about whether or not to do something. Informed consent is a really important part of research. Research can't be good unless it involves informed consent. ASAN also supports people's right to say "no" to different uses of their genetic information. People should always have the right to say "no" to research on them.

It is important that information collected for research is never used to discriminate against research participants. In the US, there are laws that protect people's genetic information. The two main laws are the Health Insurance Portability and Accountability Act (HIPAA) and the Genetic Information Nondiscrimination Act (GINA). **ASAN supports these laws. We think there should be more protections against discrimination based on genetics.**

**ASAN also believes that genetic testing should *never* affect the kinds of autism services a person receives.** We think that service providers should not be allowed to require genetic testing information in order for a person to get services.

## No genetic editing for autism

**ASAN opposes germline gene editing in all cases.** Germline gene editing is editing a person's genes that they pass down to their children. We do not think scientists should be able to make gene edits that can be passed down to a person's children. The practice could prevent future generations of people with any gene-related disability from being born. This is eugenics and a form of ableism.

Germline gene editing does not work well enough to be used, but it is being studied. ASAN believes this kind of research should be stopped. This is because there is a high risk of germline gene editing being used on autistic people eventually if it is approved for any other disability. Many people around the world, including most scientists, agree that germline gene editing should not be used in humans under any circumstances.<sup>9</sup>

**ASAN opposes non-heritable gene editing for autism.** This is when scientists edit a person's genes in a way that can't be passed down to their children. 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. We want there to be rules saying people can't use genetic research to find a "cure" for autism. We are setting this standard for autism and the autistic community because it is what most of our community members believe.

Some disability communities might want non-heritable gene editing. For example, some people with epilepsy are okay with non-heritable gene editing for the genes that cause their seizures. We think it should be up to each disability community to decide if they are okay with non-heritable gene editing for their disability. Researchers and policymakers

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<sup>9</sup> For example of such agreement, see the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine (Oviedo Convention), Article 13 – Interventions on the human genome (<https://rm.coe.int/168007cf98>).

should listen to each disability community about how that community feels about non-heritable gene editing.

## **Autistic people should be in charge of genetic research on autism**

Genetic research on autism must be led by autistic people. **ASAN calls for the adoption of field-wide ethical standards that require the leadership of autistic scientists and involvement of self-advocates at every stage of study development.**

This means that autistic scientists should run these studies. Those autistic scientists must also use community-based participatory research (CBPR) to make sure that a range of autistic people have input on the research. Genetic research on autism impacts our whole community. It should never just be one autistic researcher making decisions about genetic research on autism. Autistic people of color, nonspeaking autistic people, and autistic people with intellectual disabilities could be harmed the most by genetic research. They must have a say in decisions about genetic research. The involvement of non-autistic family members and support staff is important, but it is not the same.

Autistic people must also control how autistic genetic information is stored and used. For example, some researchers want to make big databases that collect DNA from lots of different autistic people. They want to use these databases to study autism. Some of these databases already exist. The SPARK research study collects the genes of autistic people at: <https://sparkforautism.org/>. The currently paused Spectrum 10k project is another example: <https://spectrum10k.org/>. But neither of these databases is led or controlled by autistic people. They are both controlled by non-autistic researchers.

**ASAN believes that all databases of autism DNA should be run by autistic people ourselves.** That means at least half of the people who make decisions about the database should be autistic. These autistic

people should be able to represent the autistic community broadly, and should include autistic people of color, nonspeaking autistic people, and autistic people with intellectual disabilities. They would decide who can use the information in the database and what kind of experiments the database can be used for. Autistic researchers and organizations could collect the data and run the experiments.

No known autism genetic information database is run autistic people right now. They are all run by non-autistic researchers. The research community does not have a lot of feedback from autistic people. Because of that, the research community has a lot of negative beliefs against autistic people and people with other intellectual and developmental disabilities, especially people with intellectual disabilities.

**Until genetic research and genetic databases on autism are led and controlled by autistic researchers and the autistic community, we cannot endorse any genetic research or genetic data collection project.**

## **If genetic research moves forward**

If genetic research into autism moves forward, **ASAN believes that detailed ethical standards for how this research is done must be developed.** All scientists who do autism genetic research must agree to these standards. And, the standards must actually be followed. The standards should include a plan for how to make sure that scientists follow the standards. **Autistic scientists and organizations should lead the development of the standards.**

Autistic people must lead autism genetic research. We must be the primary scientists doing this research. We shouldn't just be people the research is done on. We must lead developing good standards for autism genetic research to follow. We must be involved at every step of the way in making sure good, ethical research happens.

These are basic first steps. ASAN believes that autism genetic research can and should be held to far higher standards than we have outlined here. However, **even with these basic first steps, no autism genetic research meets our standards.** This shows how far the field has to go to develop good research and provide an ethical standard that is acceptable to autistic people.

## ***Non-genetic research has the greatest potential to improve autistic lives***

Genetic research should play a much smaller role in autism research. It should receive far less funding than it does now. In 2018, \$74.3 million, or about 1/5 of total autism research funding in the U.S., went to research into what causes autism. Most of this research was genetic research. However, only \$13.3 million, or 3/100 of total funding went to lifespan issues, or issues that affect autistic people as we grow up and age.<sup>10</sup> ASAN thinks that there should be much less funding given to genetic research into autism. Instead, more funding should go to research about services, autism across the lifespan, and other research that the autistic community supports.

**Autism research should study things that are important to autistic people.** It should study things that can help us right now, instead of trying to “cure” or stop autism in the future. It should focus on autistic people who are most often left out of actually helpful research, like autistic people of color, autistic women, autistic transgender and nonbinary people, autistic people with intellectual disabilities, and nonspeaking autistic people.

There are lots of things about autism that ASAN thinks need more research. Here are just a few:

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<sup>10</sup> Autistic Self Advocacy Network. (2021, November 22). ASAN Comments on the IACC Strategic Plan—Autistic Self Advocacy Network. *Autistic Self Advocacy Network*. <https://autisticadvocacy.org/2021/11/comments-on-the-iacc-strategic-plan/>



- What causes sensory pain, overwhelm, and meltdowns for different autistic people?
- Why do autistic people have trouble controlling our bodies? What will help?
- Why do some autistic people also have mental health disabilities like anxiety? What will help?
- Why do so many autistic people have medical conditions like epilepsy, connective tissue disorders, and problems with sleep? What will help?
- How can we help more autistic people be included in society? For example, what kinds of help do autistic adults need to get jobs?
- How can autistic people be supported to live our best lives?

Genetic research might help to answer a couple of these questions. But most of these questions aren't about genes at all. All of these questions need lots of kinds of research to answer them fully.

**ASAN thinks that all autism research should have to meet high standards.** It should have to follow very strict rules to make sure it treats autistic people fairly. It shouldn't treat the autistic people in the research badly or make us do things we don't want to do. Autism research should also be replicable. Replicable means that other scientists can do the exact same experiment again and see if they can recreate its results. Right now, a lot of autism research isn't replicable. When scientists try to redo a lot of autism research, they get completely different results. That means a lot of autism research might not be accurate.

Autism research should always be community-based participatory research (CBPR). It should be led by autistic scientists. The scientists doing the research should listen to the autistic community. They should especially listen to autistic people of color, autistic women, autistic transgender and nonbinary people, autistic people with intellectual

disabilities, and non-speaking autistic people. There should be a diverse group of autistic people advising the scientists who do this research.

Autism research should involve autistic people in every step of the process. Autistic people should lead autism research. Autistic people should also be on the ethics committees that check to make sure autism research meets ethical standards and will not hurt the autistic people taking part in it.

**ASAN's ultimate goal is for autism research to help end ableism and discrimination towards autistic people.** We want research to focus on improving autistic people's lives and the society we live in. We want research to focus on changing the social attitudes that negatively affect autistic people everyday. We do not want research to focus on changing autistic people to make us "less autistic" or "more ready" to fit into a society which rejects us.

If any researchers would like to partner with ASAN to complete ethical, standardized, replicable, high-quality, community-based participatory research, ASAN is happy to work with them. Our community needs good research. But right now, a lot of autism research is not ethical and is not good for autistic people. We need autism research to be ethical and good for autistic people before we can endorse it.