

# 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.