

ASAN Statement on Genetic Research and Autism

Recommendations

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.¹

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

¹ 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>).

be up to each disability community to decide if they are okay with non-heritable gene editing for their disability. Researchers and policymakers 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.² 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.

2 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/>

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

- 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.