



Plain Language Edition

**Autism Research and
the IACC:
Your Voice Matters!**

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To start

This toolkit is about autism research, and will answer questions like:

- What is research?
- What do people research about autism?
- What does good autism research look like?
- Why does autism research matter?
- How can everyday people affect what autism research gets done?
- What is the IACC, and why is the IACC important?
- What is a public comment, and what should a public comment say?
- Where and when should someone send in a public comment?

What is research?

Research is a way that people learn new things about the world. When people do research, they:

- Collect information about something
- Use that information to answer a question or solve a problem
- Share what they learned with others

Research is different from just learning about something, because people do research on purpose.

For example:

Keah goes to school, and she learns about gravity. Keah wants to learn more about gravity, so Keah does a research project. She decides to see how gravity affects different things. She drops different objects from the top of her bed, and sees they all fall at the same speed. Keah tells her class about what she found out, and her research helped her class learn more about gravity.

People can do research just to learn more about something, but people can also do research to help others. For example, research can help people who get sick. Some people research how to make medicines. Their research happens in a lab, and they work with chemicals.

Other people research how to help people get health care when they need it. That research might focus more on talking to doctors, or visiting hospitals. Both of these kinds of research are important.

People who do research are called researchers. Anyone can do research, so that means anyone can be a researcher! But some people do research as their job. In this toolkit, we use the word “**researcher**” to talk about people who do research as their job.

Some researchers work for colleges, while others work for the government. Some also can work for different places, like businesses. For example, researchers might work for a health insurance company. They do research to see if the company is doing a good job, and figure out how the company can help more people.

People use different words to talk about research. When someone does research, it gets called a “research project” or a “study”.

What do people research about autism?

People do lots of different kinds of research about autism. It would be hard to list every kind of autism research here, but here are some questions autism researchers ask:

- What causes autism?
- How are autistic people different from non-autistic people?
- Can autism be cured? How?
- How do we make schools a better place for autistic people?
- What kinds of health problems do autistic people have?
- How do we help autistic people live in the community?

Not all of these questions are good questions! Some autism research can hurt autistic people.

We want to make sure autism researchers do good research.

What does good autism research look like?

There are many things we think autism researchers should focus on, but these are the main things we think are important. These ideas are a good start to figuring out what good autism research looks like.

Good autism research focuses on all autistic people. That means research should get done about autistic kids and adults. Most autism research gets done just about autistic kids, even though autistic kids grow up into autistic adults. It's important to do research about autistic adults, too.

Most autism research has only studied white autistic boys and men. A lot of autism studies leave out people with intellectual disabilities. That's why we need more autism research about people of color, women and non-binary people, and people with intellectual disabilities. We need to make sure people from these groups have their voices heard in research. That is the only way we can know how to help all autistic people.

Good autism research focuses on all kinds of communication.

Communication is how we show others what we want and need. All autistic people communicate, but some autistic people talk with our mouths, while other autistic people don't. Some of us use words, while others don't.

Most autism research about communication focuses on talking with our mouths, and tries to make all autistic people talk with our mouths. But we shouldn't have to talk with our mouths to get what we need. Autism research should help us communicate the ways that work best for us, and focus on ways to communicate besides using our mouths.

Good research listens to autistic voices. Good non-autistic researchers work with autistic community members to help autistic people do research ourselves. They let autistic people decide how research projects get done.

Most of all, good research focuses on what autistic people want. We want help fixing other health problems we have, like sleep problems or stomach problems. We want help living in our communities, getting the services we need, going to school, and getting jobs.

But most autism research doesn't focus on what autistic people want. It focuses on trying to cure autism, or finding out what causes autism. It focuses on trying to make autistic people seem "less autistic".

Good autism research doesn't focus on trying to "cure" autism. Researching a cure for autism hurts autistic people. It shows that researchers don't want to accept us for who we are, and makes us feel bad for being autistic.

Other research tries to make autistic people seem "less autistic", and these research projects also hurt autistic people. They punish autistic people for being autistic, and make autistic people scared to show we are autistic. These projects don't make us "less autistic". They just make us pretend to not be autistic, and that hurts autistic people. We should get to be who we are.

Autism is an important part of who we are. We don't want to be cured, or to be "less autistic".

And trying to cure us doesn't help us live our lives now. It just takes money away from research that can help us.

Why does autism research matter?

Autism research is really important because research affects policy. A **policy** is a rule or law the government makes. Making new policies takes a lot of time and energy from the government, so the government wants to make sure they pass good policies. They look at research to see what they should do.

Here is an imaginary example of how research can affect policy:

Dwayne is an autism researcher, and researches how autistic kids do in school. He finds out autistic students need a lot of breaks to do well in school, but most schools don't have quiet space for students. There is nowhere to take a break if someone needs one, which makes it a lot harder for autistic kids to learn.

Dwayne asks the government to make a new policy. This policy would tell schools to make a break room that students can choose to use. Dwayne's research shows how the policy would help a lot of students, so the government passes the policy.

Dwayne could also ask the government to make a different policy. He could ask for more breaks to be put in school schedules, which would also help autistic students.

One research project can affect policy in many different ways!

Most autism researchers are not autistic themselves. Doing research as a job is hard, even for non-disabled people. But it can be extra hard for disabled people. Research gets written using long, difficult words, and most research jobs make their workers get college degrees. It can be harder for disabled students to pay for college, and college can be an unfair place for autistic students. That's why not everyone can get a degree, which means not everyone can become researchers. That isn't fair! Our voices get left out of conversations about autism research.

Not many autistic people become researchers, and many autism researchers don't try to talk to autistic people. That's why autism researchers come up with bad research questions. These questions don't help autistic people live better lives. That's why researchers need to hear from autistic people. Nothing about us, without us!

There is one big thing you can do to affect what autism research gets done: talk to the IACC!

What is the IACC?

IACC stands for "Interagency Autism Coordinating Committee". We call them the "IACC" for short. **The IACC** is a group of people chosen by the government, and they help decide what autism research the government will pay for.

The U.S. government sets aside some money for autism research. The IACC helps them decide how to spend that money. The IACC meets every 3 months to look at autism research projects being done. They talk to autism researchers about what the projects found out. They ask researchers to focus on certain kinds of autism research projects, and ask the government to pay for certain kinds of autism research projects.

The IACC has 43 people on it. There are lots of different kinds of people on the IACC, like:

- People who work for the government
- Autism researchers
- People who give autistic people health care
- Autistic self-advocates
- Parents of autistic people
- People who work for autism organizations

Some IACC members work for the U.S. government, and are called **Federal members**. Some IACC members do not work for the U.S. government, and are called **public members**. There are 22 Federal members, but none of the Federal members are autistic. There are 21 public members, and 6 of the public members are autistic. That means 6 out of the 43 total IACC members are autistic. That is more autistic people than there used to be, but we still think the IACC should have more autistic members.

What the IACC does is really important! The government has a set amount of money for autism research, so they should pay for research that helps autistic people.

It would be bad if the government paid for research that hurts us, and extra bad if that research affected policy later on. Remember, research can change the rules and laws the government makes. That could make life a lot harder for autistic people.

Talking to the IACC is the best way to make your voice heard. You can help the IACC learn what autistic people want researched!

How can I talk to the IACC?

You can talk to the IACC by sending in a public comment. **Public comments** are ideas people send to the government. People tell the government what they think the government should do, like how a certain law or rule should work.

The money set aside for autism research got set aside because of a law, and that means people can make public comments about that money. They can tell the government how they think the money should get spent.

Usually, everyday people don't send in public comments, and most people don't even know what a public comment is! Sending in a public comment can be confusing, but that's why sending in public comments is so important. The government needs to hear from people it doesn't usually hear from, like everyday autistic people. That is how the government can make policies that help us.

Where and when should I write a public comment?

You can send a public comment over email to IACCPublicInquiries@mail.nih.gov.

You can also send it through the IACC website at <https://iacc.hhs.gov/meetings/public-comments/submit/index.jsp>.

You can send in a public comment any time, and it will get given to the IACC members at their next meeting. Remember, the IACC has meetings every 3 months, and they post when the meetings happen on the IACC website.

Sometimes, the IACC will ask for public comments about something specific. They might ask about a certain research project or kind of autism research. The IACC will post chances to make public comments like these on their website. You only have a short time to send in comments like these, and the deadline will also be posted on the IACC website. Be sure to check when the deadline is, and send your public comment in time!

Autism organizations also post about the IACC on their websites or social media. ASAN posts about the IACC at <https://autisticadvocacy.org/tag/iacc/>.

You can follow this page to find out when to send in public comments, and the page also has ideas for what you can write to the IACC about.

What should I write in a public comment?

Here are some tips for writing your comment:

- Think about the most important thing you want the IACC to know. What kind of questions about autism do you think researchers should study? What problems do autistic people have that research should try to solve?
- Try to be as specific as possible.

For example, don't say "The IACC should tell the government to study sleep". Instead, say "Lots of autistic people have trouble sleeping, so I think more research should get done on sleep problems in autistic people. The IACC should ask for research that helps autistic people sleep better."

- You should only write 1000 words or less for your comment, since the IACC might not read more than the first 1000 words.
- Do not put private information about your life in your comment, or send pictures or videos.

- Only send in a comment you write yourself, since the IACC won't read doubles of the same comment.
- Sometimes the IACC will ask about more than one thing to comment on. You can answer the questions you want to answer, but you don't have to answer all of the questions.
- If you use the IACC web form, you have to hit "Submit" at the end of the form. Otherwise, your comment won't be saved.

Public comments to the IACC can be hard to write, since they have to get written a certain way.

Here is a guide for writing your public comment:

Dear IACC,

My name is **[full name]**. I would like to talk to you today about autism research. I think the IACC should tell the government to pay for autism research about **[topic]**. I think this kind of research is important because **[reason]**.

[Here is where you can share more of your reasons. You can talk about being autistic, or knowing autistic people. Show how the research you're talking about would help autistic people.]

I think the IACC should listen to the voices of autistic people the most. The research I talked about is important to autistic people, and it might answer questions we have about our lives.

It could solve problems autistic people have, so we can live the lives we want. Please help autistic people by asking for more research about **[topic]**.

Thank you for reading my comment.

Sincerely,

[Your name]

You can also look at the [Sharing your Story](#) toolkit. It has tips for how to write your ideas to the government.

What happens after I send in my public comment?

You won't hear anything back from the IACC when you send your comment. You might not hear back from the IACC at all, but your public comments will still get seen.

The IACC meetings are not that long, so there isn't time to read everyone's public comments at the meeting. But the IACC has to read every public comment people send in. The IACC will read the comments before the meeting, and I think about the comments during the IACC meeting.

They will tell the government about the comments. Your comments can affect what the IACC tells the government, and what autism research the government pays for!

The IACC may also post your public comment on their website. Be sure you are okay with that before sending in your comment.

If you would like to watch the IACC meetings, you can check the IACC website. The IACC meetings are open for everyone, and get live streamed on the IACC website.

The IACC meetings can be difficult to understand. Try talking to advocacy groups that care about autism research. They can help you understand more about what happens during the meeting.

Keep checking the IACC website, and websites of autism groups. They will tell you about more chances to advocate for good autism research. You can keep making a difference in autism research.

Research about autism happened without listening to us for a long time, and today, many researchers still don't listen to us. Policies got made without asking what would help autistic people. Now is our chance to stop that from happening any more, but we have to make our voices heard. That starts by talking to people like the IACC. Nothing about us, without us!

Words to Know

Communication

How we show others what we want and need.

Federal members

IACC members who work for the U.S. government.

Policy

A rule or law the government makes.

Public comments

Ideas people send to the government. People tell the government what they think the government should do.

Public members

IACC members who do not work for the U.S. government.

The IACC

A group of people chosen by the government. They help decide what autism research the government will pay for. IACC stands for “Interagency Autism Coordinating Committee”.

Research

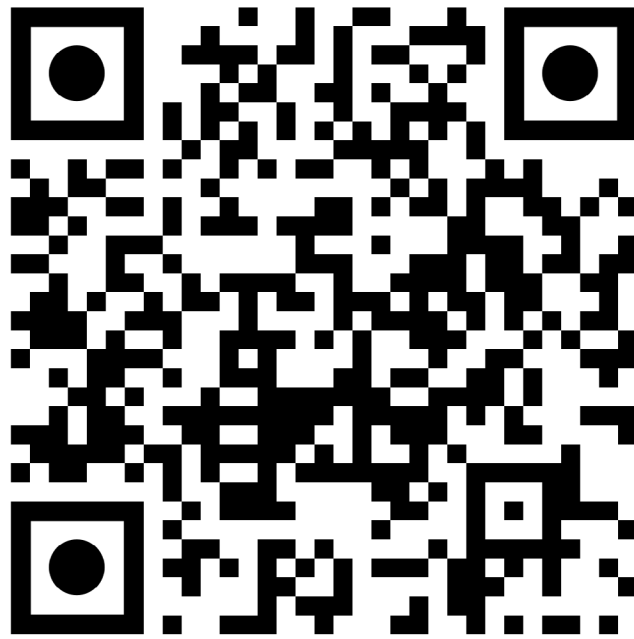
A way that people learn new things about the world. Research happens when people try to answer questions or solve problems.

Researchers

People who do research as their job.

Want to share your thoughts on
this toolkit?

Take our survey!



Scan this code with your phone
to go to our survey.

Or, go to

[www.surveymonkey.com/r/
ASANresource](http://www.surveymonkey.com/r/ASANresource)