Easy Read Edition

Autism Research and the IACC: Your Voice Matters!

Part 4: What does good autism research look like?
Words to Know in Part 4
Communication

How we show others what we want and need.

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.
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.

But 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 people.

Most autism research also only studied boys and men.

A lot of autism studies leave out people with intellectual disabilities.
We need more research about autistic people of color.

We need more research about autistic women and non-binary people.

We need more research about autistic 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. 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.

It 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.

It should focus on ways to communicate besides using our mouths.
Good research listens to autistic voices.

Good non-autistic researchers work with autistic community members.

They 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.

For example, sleep problems or stomach problems.

We want help living in our communities.

We want help getting the services we need.
We want help 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.

It focuses on trying to find out what causes autism.

It focuses on trying to make autistic people seem “less autistic”.

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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.

It makes us feel bad for being autistic.
Other research tries to make autistic people seem “less autistic”.

These research projects hurt autistic people.

They punish autistic people for being autistic.

They 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.

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. We don’t want 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.
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