

AAC Research Priorities: In Plain Language



Join us in making AAC research better for everyone!

You can help!

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What is this guide about?

The government is asking people what kind of research should be done about AAC and AAC users.

AAC users should have a say in research about us and our lives.

So, we are asking AAC users to tell the government what kind of research about AAC is important to you.

But most people haven't had a chance to think about what kind of research is important to them.

CommunicationFIRST wrote this guide to help you think about research. This guide will also help you understand how research can affect you as an AAC user.

After you read this, we hope you will tell the government what kind of AAC research you think they should pay for.

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What is research?

Research is a way to learn more about something. When someone does research, they hope to learn something new.

A **researcher** is what we call someone who does research. Researchers do a lot of reading to learn about the thing they are researching. The thing they are researching is called a **research topic**. Then they think about what they still don't know about their research topic. They come up with questions called **research questions**. These questions are what they are trying to answer in their research.

Who does research?

There are different kinds of researchers. Some researchers work at universities and colleges. Some researchers work for organizations and businesses. Some work for the government.

Some researchers invent solutions and test them. For example, they might invent a new AAC device. They might ask AAC users about their idea first, or they might test their device with AAC users.

If AAC users are given a lot of control in this process, it is called **participatory research**.

Usually, researchers do **not** work together with AAC users in choosing and designing their research projects. Or, they might only include them very late in the project, after most decisions are already made.

Most AAC researchers do not use AAC themselves.



How do you do research?

Once a researcher comes up with a research question, they must figure out how to answer it. The way that they find this answer depends on their question, and what they think might work best.

There are many ways to do research. Research can happen in a lab where researchers do experiments. Or, researchers might talk to people in person or online in **interviews**. During an interview, someone who knows about the topic tells the researcher about their experiences.

How does research help us learn?

Everything that researchers learn while they are doing research is called **data**. Data is information. Data can be all sorts of things. Data can be numbers (like the number of words you type in a day). Data can be words (like your name). Data can be things about you and your life (like your health and education).

All data can be important in its own way. But not all data should be available to everyone. Some data should be **private**. Privacy helps to make sure that nobody can use your data in ways that could hurt you. Privacy helps to protect you.

Researchers work hard to make sure your data stays private. This is called **confidentiality**. Confidentiality also means that you have the right to understand how researchers will use data about you. You also have the right to understand how researchers will protect data about you.



How do researchers use data?

Researchers **analyze** the data they have gathered. That means they look for patterns in the data. These patterns can help them learn new things. The new things they learn are called **findings**.

Researchers write about their findings and share them with other researchers. They might do this at a **conference**, where many researchers get together. Or they might put their findings in a book or academic journal. These are called **publications**.

Some publications are easy for anyone to read. Other publications can be hard to access and understand.

What do we do with what we learn?

Research fills in the gaps of things we do not know. This can help us solve problems. Research can:

- Help other people understand people who use AAC better
- Help other people do a better job of finding the right type of AAC for you
- Help other people do a better job of helping you to learn and use AAC
- Help teachers do a better job of teaching you in school
- Help the government write laws that protect AAC users better
- Help doctors understand how to take care of AAC users better
- Help people understand how to build better AAC
- Help solve other problems that are important in your life

Research can change the world for people who use AAC.



What is participatory research?

You can be a part of **participatory research**. In participatory research, the people researchers are learning about – like AAC users – are part of the research team. They help guide and oversee the research, from the beginning to the end. Participatory research is important for AAC research, because:

- You know your life and your experiences better than anyone else. **You are the expert!** The things you have to share are important.
- Without your help, people who don't use AAC are more likely to make mistakes in their research. They might assume things about AAC users that are wrong. They might misunderstand important data.

What is a research priority?

A research priority is an important question or topic that we don't know enough about.

Researchers who don't use AAC might not understand what questions are important to us. These important questions are called **research priorities**.

Researchers need to have the right research priorities, or the research we need won't get done. That could mean we are missing out on important information. It could mean people aren't getting the right help or the help they need to communicate and be accepted.

When you are asked what your research priorities are, you are being asked what topics are important to you, or what questions you believe must be answered so you can live a better life.



What research exists about AAC and AAC users?

There is lots of research about AAC and AAC users. Because of research, we have gotten better at things like:

- Choosing an AAC system for a person, based on what they need and want
- Helping people get used to their AAC system
- Making AAC easier to get and use in everyday life
- Helping AAC users live better lives
- Understanding the AAC needs of people from different cultures
- Using new technology to design new kinds of AAC

AAC is important. Everyone who cannot use speech to be understood needs AAC.

What do we still need to learn about AAC and AAC users?

Even though we know all of these things, there are still a lot of problems with AAC research. And we know there is a lot of research that still needs to be done to improve our lives.

New research can help:

- Make AAC that meets our needs better
- End our loneliness and isolation
- Make sure all AAC users get a good education
- Make sure all AAC users who want to work are able to get a job, keep a job, change jobs, and have a career
- Make sure we get good health care



- Make sure we can live safely in our homes and communities, and call for help if we need it
- Teach other people that we have important things to say, and that we can succeed in life
- Teach other people that AAC is one tool that helps us be understood, and there's much more to each of us
- Let us make decisions about our own lives, including where we live and how we want to be supported
- Let us keep our rights and be able to vote after we turn 18

Why does AAC research need to change?

AAC research isn't helping the people who need it the most. Some people still believe old myths about AAC. For example, they might think that someone can be “too disabled” to use AAC. These beliefs can be harmful. Because of these beliefs, some people might not get the AAC they need.

AAC research can be biased. Researchers aren't perfect. Sometimes, researchers are biased. **Bias** is an unfair or untrue belief that changes how you think about the world or people. Someone might not notice if they are biased. When someone makes decisions without thinking about their biases, the results can hurt people.

AAC research can be ableist. Ableism is the idea that being nondisabled is better than being disabled, and that people with disabilities need to be cured or changed. For example, researchers may assume that the “right” outcome for all people with speech disabilities is to learn to speak aloud. They may work very hard to try to make us speak, without working very hard to get us good AAC.

AAC research does not usually include people who need AAC. That means that questions that are most important to us might never even be asked by researchers. Or, researchers might make the wrong assumptions about us and our lives. For example, they might assume that AAC users only have one type of disability, or never interact with other disabled people, or only need to communicate with people who speak English.



AAC research can exclude. When someone is excluded, it means they are left out. A lot of AAC research focuses on only one disability or condition.

We think that taking a **cross-disability approach** could help AAC research. That means looking at how disabilities are similar to each other. Some of our needs may be a bit different, but our needs to communicate, to be understood, and to make decisions about our own lives are the same.

Research is powerful. Biased research can make ableism worse. For example, when research assumes that we can't speak because we can't understand, people treat us like we can't understand. This is **discrimination**.

But research can also help **prevent** bias, ableism, and discrimination. For example, when research shows that we can use language when we have the right tools, people will try harder to help us find the right tools.

What can I do to make research better?

The government is asking AAC users to share their ideas for the most important types of research about AAC and AAC users. The government will use these ideas to choose which research to pay for.

The government is asking about four different topics. Here are plain language versions of each of the topics:

- **TOPIC 1:** What does AAC need to do for people that it isn't able to do yet? What changes do we need to make to make AAC better?
- **TOPIC 2:** What are the hardest parts about using AAC to communicate with other people? What makes it hard to get tools and supports for communicating?
- **TOPIC 3:** What kinds of changes would help AAC users communicate and be understood better? What questions do you have about AAC and speech disability that you don't have answers to? What are some of your biggest worries as an AAC user?



- **TOPIC 4:** What would make it easier for AAC users to talk to researchers about their experiences? What makes it hard to talk to researchers right now? What does good research look like to you? What does bad research look like to you?

They would like to hear from you by **September 15, 2023**.

CommunicationFIRST made a long list of some research ideas. This list might help you think about what is most important to you. [You can see the list here](#).

How do I share my ideas with the government?

You can send your comments by email to: NIDCDMinVerbRFI@nidcd.nih.gov.

Or you can put your ideas [in a form on this website](#). The form only lets you submit short answers, so if you have a lot to say, you should write out your thoughts in a document and then email it, instead of using the form.

The government will not send you a message back, but they will read what you write.

CommunicationFIRST wants to know what kind of research is important to you, too! Please send a copy of your comments to CommunicationFIRST at info@communicationfirst.org so we can hear from you about your priorities.

CommunicationFIRST won't respond to your message, either, unless you ask us to.



Words to know

Ableism

Ableism is the idea that being nondisabled is better than being disabled, and that people with disabilities should be cured or changed. Ableism says that some ways of being human are “normal,” right, and better, while other ways of being human are “abnormal,” wrong, and less. Ableism causes bias, discrimination, and violence against disabled people.

Ableism is a system. This means that everyone learns ableism as they grow up. But we aren't stuck! We can learn new ways of thinking about disability. For example, we can value AAC just as much as speech.

Analysis

When you analyze something, you study it to find patterns and learn new things. Analysis is an important part of research.

Bias

Bias is an unfair or untrue belief that changes how someone thinks about the world or people. Bias can cause discrimination.

Conference

A research conference is a meeting where researchers share new ideas. Conferences can be in person or virtual. Often, you can go to a conference even if you are not a researcher, although it might cost money.

Confidentiality

Confidentiality is when private information stays private. It also means that you understand how researchers are using information about you.

Cross-disability

When something is cross-disability, it includes people with lots of different disabilities.

Data

Data is information. Data can be numbers, like the number of words you type in a day. Data can be words, like your name. Data can be things about you and your life, like your health and education.



Discrimination

Discrimination is when you are treated differently because of bias or a system like ableism. For example, when a researcher speaks to your parents instead of you because they assume you cannot understand them, that is discrimination.

Exclusion

When someone is excluded, it means they are left out. For example, some people with certain conditions might be excluded from AAC research, even though they also need AAC.

Findings

Research findings are the new things that a researcher learns from their research.

Interviews

During a research interview, a researcher asks someone questions about their experiences.

Participatory research

Participatory research is when the community being studied is a part of the research process. People from the community help come up with ideas and questions. They help researchers understand the best way to communicate with others from their community. They help researchers understand patterns in the data. This participation makes research better.

Privacy

In research, privacy is when some of your information is kept secret. Privacy helps to protect you.

Publications

Researchers publish their findings in publications, where other researchers can learn about what they found.

Research

Research is a way to learn more about something. When someone does research, they hope to learn something new.



Researchers

A researcher is someone who does research. Although anyone can do research, when we talk about researchers, we usually mean people whose job is doing research. Researchers might work for universities, companies, or the government.

Research priorities

A research priority is an important question or topic that we don't know enough about. Researchers need to know about priorities so they know which questions to ask and answer in their research.

Research questions

Researchers design their research to answer research questions. For example, a research question in AAC research might be, "What are the best ways to help children learn a new kind of AAC?"

Research topics

Research topics are what the research is about. All AAC research is about AAC. But research topics can get more specific, too. For example, AAC research might be about a certain kind of AAC, about loneliness in AAC users, or about people who use AAC in more than one language.