



What is this document?

This is a plain language version of the AAC Counts project report.

AAC Counts is a project by CommunicationFIRST and the Disability Rights Education and Defense Fund (or DREDF).

We got money to write it from Ability Central.

The long version of the AAC Counts report is in three parts. You can read the long version here: <https://communicationfirst.org/aac-counts>.

This plain language version was written by Ren Koloni. Ren works for CommunicationFIRST. They are autistic and a part-time AAC user. They identify as cognitively disabled.

Many AAC users also use plain language to understand things that are important to them. AAC Counts talks about things that are important to AAC users.

We want to include all AAC users when we talk about things that affect them - not just ones who can, or want to, read the long version of the report.



What is AAC?

Everybody has ways to communicate that are not speech.

- We might point to things.
- We might look at things.
- We might make expressions with our faces to show how we feel.

But not everybody communicates with speech.

Many people think speech is more important than any other kind of communication. But this is not true.

People who can't (or can't always) use speech to communicate - people with speech disabilities - need to use AAC in order to be understood by other people.

AAC stands for **A**ugmentative and **A**lternative **C**ommunication. AAC is any kind of tool that helps support your spoken words, or that you use instead of spoken words.

AAC might be:

- A letterboard. You point to letters to spell out the words you want to share.
- A speech-generating device. You type or choose words, and the device speaks them aloud.
- A revoicer. You speak words, and a revoicer says them again, more clearly, faster, or louder.
- And many other things.

Some people believe that gestures and facial expressions count as AAC. CommunicationFIRST says that these are not enough.

We believe in **communication equity**.

Communication equity means that everyone is able to express themselves, about whatever they want, whenever they want, in whatever way they want to.



To get to communication equity, people who can't use speech to be understood need **language-based AAC**.

People need to be able to talk about things that they can't point to. People need to be able to talk about complicated things. People need to be able to form sentences. You cannot do these things with gestures or facial expressions.

When we talk about AAC in this report, we are talking about language-based AAC.



What is AAC Counts?

AAC Counts is a project to show that we need to learn more about people who need AAC.

People who need AAC can't just use spoken words to be understood by other people. They need to have AAC.

But many people who need AAC do not have access to AAC. That means that they are not being understood by the people around them.

They might not be able to tell people how they are feeling. They may not be able to tell people when they are upset or hurt. They may not be able to talk about what they need or want.

They might feel lonely or depressed. They might not be able to talk to their loved ones or people in their communities.

We wanted to find out **what we know** about people with speech disabilities. We also wanted to find out **what we don't know** about people with speech disabilities.

We looked at statistics. We looked at research. We looked at surveys. We put what we found into this report.

We thought about what was missing.

We came up with ideas for how to find out things we still need to know.



For example...

How many people need AAC in the United States?

The short answer is, we're not sure. We need more information.

Here's the long answer.

We know that a lot of people have some kind of problem with their speech.

In 2012, a special survey from the National Health Interview Survey found out that 7% of the population had a voice, speech, swallowing, or language problem that lasted more than a week.

That is about 16.5 million people!

But how many of these people need AAC?

For a long time, researchers used a percentage of 0.8% of the population. That was because the American Speech-Language-Hearing Association, or ASHA, announced that they thought that was about the number of people who couldn't speak at all, or who had a lot of trouble speaking.

New estimates, though, put the percentage at closer to 1.5%. In 2021, that was almost 5 million people.

But how accurate is this estimate? Is it really 5 million people?

We won't know until we get better information.



Why is data so important?

Data is information. Data helps us understand things from many perspectives.

We need data about people who need AAC so we can make their lives better.

People who need AAC get ignored. They get treated as disposable and not important. They get treated as though what they want and what they feel doesn't matter.

Agency is the ability to make choices about your life. Agency is important for everyone, but especially for disabled people. We should be the people making decisions about what happens to us.

People often assume that we can't make decisions for ourselves. But they also often don't give us the tools we need to tell them we can make decisions! That isn't fair.

We cannot be silenced any longer. We need to be heard. We deserve to exercise our agency.

There are lots of ways to make ourselves heard. One way is by helping make policy changes.

When big change happens in the United States, it's called policy. Policy means changing the law, giving money to projects, or making new organizations. Policymakers make these big changes.

Policymakers need information that is accurate and detailed. That way, they can:

- Know what policies they need to make,
- Argue to other people that we need to make these policies, and
- Measure how well their policies are working.

The Americans with Disabilities Act, or the ADA, is one example of policy. The ADA helps make sure that people with disabilities in the United States have civil rights.



The ADA says that people can't discriminate against people with disabilities. That means that people with disabilities have to be treated fairly.

Without data on people who need AAC, we don't know if the ideas in the ADA are making a difference in their lives.

If we learn more about people who need AAC, we can find out what kind of help they need the most. We can get them the help they need.

What do we still need to learn more about?

- **How many people in the United States have speech disabilities?**
What kinds of people have speech disabilities? What communities, backgrounds, and cultures do they come from?
What language does their community speak? Do they have access to AAC that lets them speak that language with their community?
- **What are people with speech disabilities most worried about in their lives?**
- **How many of us do not have access to AAC?**
How long did we have to wait until we could get AAC?
Is it harder for some people to get AAC than others?
- **Are we getting the same opportunities at school?**
Are we a part of classrooms that include disabled and non-disabled people?
How many of us can read?
How many of us go to college?
- **How many of us have to deal with guardianships after we are adults?**
(Guardianships are supposed to help people with disabilities make decisions. But they are not always helpful. People under guardianships lose rights that other people have, like the right to marry or vote. They cannot make choices that all people should be able to make, like where they want to live, or how they want to get health care. Guardianships can be dangerous. They can be especially dangerous for people who need AAC, but don't have it.)
- **Are we getting the same opportunities at work?**
Are we being treated fairly at work?
Are we earning enough money to live well?
- **Are we getting the healthcare we need?**
- **How many of us live in institutions or group homes?**

AAC COUNTS

- How many of us are getting hurt or abused?
- Are we getting the same opportunities in the justice system?
- Do we get the chance to have good friends, or get married if we want to?



How do we answer these questions?

The government of the United States makes surveys and asks lots of people questions about their lives. That way, they know who lives in the United States and what they need in their lives.

But the government does not ask these questions about people with speech disabilities.

Right now, we don't have good information about people who need AAC.

We can tell the government that we need help, but we need to know these things about our population so we can say what kind of help we need, and why.

When we know what kind of help we need, and why, we are more likely to get the things we ask for. And, those things are more likely to be able to help people in our community.

The government needs to collect information about people with speech disabilities through big surveys, like the American Community Survey, or ACS.

Big surveys are the best way to get information on people with speech disabilities, because we are so diverse. There is no one easy way to find out more about all of us.



What surveys already ask about people with speech disabilities?

The National Health Interview Survey (NHIS)

Since 2019, the NHIS has asked the question: Do you have trouble understanding others or being understood? But this question isn't helpful. Trouble understanding other people and trouble being understood are very different problems. We can't tell from this question how many people need AAC.

The NHIS had a special survey in 2012, on voice, swallowing, speech, and language problems. Most of the information we have about people with speech disabilities in the United States comes from this survey.

The NHIS doesn't include people who live in institutions, like nursing homes or group homes.

The NHIS doesn't ask about AAC.

The National Survey of Children's Health (NSCH)

The NSCH asks if a child has ever been diagnosed with a speech disability.

This survey is only for children, and only if children got a diagnosis. It doesn't include children who live in institutions.

It doesn't ask about AAC.

The National Health and Aging Trends Survey (NHATS)

The NHATS asks if someone has a speech disability.

This survey is only for elderly people.

It doesn't ask about AAC.



The Minimum Data Set (MDS)

The MDS is a survey that asks about people who live in nursing homes.

It asks two questions about speech disability. One question is about how clearly a person speaks. Another question is about whether they can make their needs and wants understood by others.

This survey helps us know more about people with speech disabilities who live in nursing homes. But, it doesn't ask about AAC.

The Medicare Current Beneficiary Survey (MCBS)

The MCBS is for people using Medicare, a program where the government helps certain people get healthcare.

It has two different surveys: one for people living in their community, and one for people living in institutions. It only asks institutions whether people have a speech disability. That means the MCBS doesn't ask people who live in their own homes or with their families if they have a speech disability, even though lots of people do.

It's missing an important part of our population, and it doesn't ask about AAC.

The National Beneficiary Survey (NBS)

The NBS is for people who get SSI or SSDI, programs where the government helps certain people get enough money to live.

It asks if someone has a speech disability.

It doesn't ask about AAC.



The National Core Indicators surveys

National Core Indicators, or NCI, is a project that focuses on people who get services from their state. It has two parts: NCI-IDD, which stands for Intellectual and Developmental Disabilities, and NCI-AD, which stands for Aging and Disability.

NCI-IDD gives us a lot of information about people with I/DD who also have speech disabilities. It asks about how someone usually communicates.

NCI-IDD found out that almost 25% - an entire fourth - of people who responded to their survey don't use spoken words to communicate. Out of those nonspeaking people, most of them - 96% - don't have AAC devices. (But about 6% use sign language or fingerspelling.)

NCI-IDD also found out more about nonspeaking people. They were more likely to be watched all the time than speaking people. They were more likely to live in institutions. They weren't as healthy. They said they were more anxious about their safety. They weren't able to participate in their communities as much. They had much, much less ability to make choices about their lives.

NCI-IDD asks questions directly to people with I/DD. This approach is really important. Research says that you find out better and more true information when you talk to us directly. No one knows how we feel better than we do.

One problem with NCI-IDD is that it only talks to people with I/DD who get services from their state. Not all people with I/DD get services. Also, it doesn't have information from all states. And, it's only people with I/DD, not all kinds of people who have speech disabilities.

What about NCI-AD? It hasn't learned its lesson from its partner survey, NCI-IDD. Right now, NCI-AD does not ask any questions about speech disability. It used to ask if someone used a speech device, but it hasn't asked that question since 2015.



What else do we know about people who need AAC?

1. Many people who need AAC don't have it.

Many people who use AAC now had to wait a very long time to get it. We need to know more about who still needs AAC, and why they don't have it yet.

2. We don't know enough about the demographics of people who need AAC.

Demographics are important parts of identity, like gender, race, where someone was born, or how old they are.

3. We know that people who are Black, indigenous, or people of color have more problems getting AAC.

But we need to know more about the problems they have.

4. People who use languages that aren't English have a harder time getting AAC that works for them.

5. Students who need AAC don't get all the same opportunities as speaking students.

One study found out that only 1.1% of nonspeaking students who use AAC got to be in regular classrooms with non-disabled students.

This study also found out that students who use AAC are not getting taught how to read as well as students who don't use AAC. Only 3% of nonspeaking students who use AAC could understand things they read.

6. People who need AAC might be more likely to live in institutions.

A court decision called the *Olmstead Decision* said that people with disabilities should be able to live in their communities, instead of institutions. Lots and lots of disabled people now live in their communities.



But people who need AAC, especially if they don't have it, might still be living in institutions.

We also need to learn more about how guardianships affect people who need AAC.

7. People who need AAC might be more likely to not have enough money to live well.

We don't know much about people who need AAC and jobs or money.

But we do know that children with speech disabilities are more likely to live in poverty. They are more likely to live in families that don't have enough money to live well.

8. People who need AAC have more health problems, but more trouble getting care.

9. People who need AAC might be more likely to be abused.

In one study, 67% of people with a speech disability said they were abused. 66% said they have been bullied. 24% said they have been sexually assaulted.

10. We know that we don't know enough about people who need AAC.



What do we recommend?

1. More surveys need to ask about speech disabilities.

Surveys that find out a lot of information about people with disabilities in the United States should ask about speech disability.

If the American Community Survey, or ACS, asked about people with speech disabilities, we could find out so much about our community.

Because the ACS is such an important survey, other surveys that learn other kinds of information would probably start asking about people with speech disabilities, too.

At the very least, surveys that ask about important health information should ask about speech disability.

2. The NHIS question needs to be fixed.

Right now, it isn't gathering helpful information. It puts people who have trouble understanding and people who have trouble being understood in the same group.

A new NHIS question could ask, "Do you have trouble speaking, or being understood when you use speech?"

This question would be much better at finding out how many people have speech disabilities.

3. The government should make sure there is enough money for all this research to keep going.

It is not enough to have one supplement every ten years about us.

We need long-term data. Long-term data will show how our needs change over time. This is especially important because lots of us need AAC for our whole lives.



Research needs money. The government should make sure that researchers have enough money to do research now, and keep doing research for years to come.

4. Researchers should talk to us directly.

We know the most about ourselves.

Researchers shouldn't ask our parents, guardians, teachers, or doctors about us. They should talk to us directly.

They might need to learn different ways to communicate with us. But that is worth the time and effort. We have important things to say.

If we need more help responding to surveys, researchers should try to use "assisted response." In assisted response, a researcher asks someone who knows you very well to help you answer their questions. The person who knows you doesn't answer for you. They are there to help you answer for yourself.

5. Many government agencies can help make the U.S. a better place for people who need AAC.

Agencies like:

- The U.S. Census Bureau
- Centers for Disease Control and Prevention (CDC)
- The Department of Education
- The Department of Justice
- The Department of Health and Human Services (HHS)

...can work together.

These agencies can:

- Do research on people who need AAC
- Guide people, groups, and states to collect better information on people who need AAC

AAC COUNTS

- Add questions about people who need AAC to the surveys they already have
- Learn more about people who need AAC, so they can make sure they are helping in the ways they should

Some actions might be easier than others. Here is an example of a simple action that could make a big difference.

The Department of Education can tell states that it would be helpful to add a checkbox to IEPs about AAC.

An IEP is an Individualized Education Program. It helps teachers know how to support students in the classroom. But we can also use IEPs to help us understand how many students need certain kinds of help. A checkbox would help us learn how many students need AAC, and how many students actually have AAC.