



# The Words We Use

## What is this guide about?

This is a plain language version of CommunicationFIRST's style guide.

You can read the formal language version of this guide [here](#).

You can read a short version (in formal language) [here](#).

This style guide explains the words CommunicationFIRST uses when we talk about people in our community.

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Many AAC users use plain language to say and understand things that are important to them.

All people should be able to understand why we use the words we use to talk about them.

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1629 K Street, NW, Suite 300, Washington, DC 20006  
<https://CommunicationFIRST.org/>



## 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 be understood by other people may use AAC.

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

Language-based AAC is when you use words to communicate, but not with speech. Language-based AAC tools are things like:

- A speech-generating device. You type or choose words, and the device speaks them aloud.
- A letterboard. You point to letters to spell out the words you want to share.



- A revoicer. You speak words, and someone says them again, more clearly, faster, or louder.
- Writing. You use a pencil to write the words you want to say on paper.

People without language-based AAC communicate, too. They might move around, point or look at things, make sounds, smile, frown, or nod. This is AAC, too.

A person might use just one kind of AAC, or many different kinds of AAC.



## **Why are words so important?**

For a long time, other people made all the decisions about the words they use to talk to us, or about us.

Without the tools we need to be understood, we could not tell them when we felt like the words they used were wrong or unfair.

We could not tell them when the words made us feel uncomfortable or upset.

Now, more than ever, we can show people who we are, and how we want to be known.

**We are finding our own voices.**

**We are telling our own stories.**

**We are naming ourselves.**

**We are choosing our words carefully.**

Choosing better words can help us make a better world for everyone.



## How are we choosing these words?

The words that we use for ourselves need to be accurate. That means they need to tell the truth about our experiences.

But choosing the best words can be hard.

### **People who use AAC are diverse.**

Even though we all use AAC, our experiences are very different.

Some of us have never been able to speak. Some of us started to have trouble speaking when we got older.

Some of us can speak only sometimes. Some of us can be understood by a few people, who know us very well. Some of us cannot speak even a little bit.

All of our stories are important. When we talk about these stories, we want to include everyone.

Even if one part of our community says they like a word, another part of our community might say that it doesn't describe them. It might even hurt them.

That means that talking about the words we use can be hard. But it is important.

We will keep talking about the words we use. **We will keep learning.**

We will listen to all AAC users.



## How do we decide what words are helpful, and what words are hurtful?

Words that are helpful:

- Make us feel proud of who we are.
- Show that we have abilities and potential.
- Describe our experiences honestly.
- Show that we are human.
- Are **our choice**.

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Words that are hurtful:

- Make us feel bad about who we are and what we need.
- Make it seem like we are not as good as other people.
- Suggest that we will never be able to communicate.
- Make other people feel like they can't understand us.
- Try to avoid talking about the real problems we have.



## What words does CommunicationFIRST use to describe our community?

Right now, we say **people who cannot rely on speech alone to be heard and understood.**

We use these words because:

1. We think that these words include everyone in our community, no matter what their disabilities and experiences are like.
2. It tells people that we have something to say, and that they need to listen.
3. It shows that communication goes two ways. We need to be able to share our thoughts, **and** other people need to listen to us.
4. It respects people who don't think of themselves as disabled.

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We sometimes use other words in plain language, too:

- **People with speech disabilities**
- **AAC users** (or, **people who use AAC**)
- **People who need AAC**

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There are some longer phrases we use when we are not writing in plain language, like:

- **People with communication access needs.** This describes anyone who can't use their body to make spoken words that others can understand, and needs tools or help to be understood.
- **People with expressive communication disabilities.** This describes anyone who has trouble being understood when they speak.
- **People who cannot use speech as their primary means of expression.** This describes anyone who has trouble using speech all of the time.

These words may not be the best for plain language readers.

So, we try not to use them when we are talking or writing in plain language.

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Finally, when someone uses a word for themselves, we will always respect their choice.

We will use the word someone chooses for themselves, even if it is a word we usually try to avoid.





## What words does CommunicationFIRST avoid when we talk about our community?

### 1. **Nonverbal**

This word comes from words that mean “no language.”

Sometimes, when people use **nonverbal** to talk about someone who cannot speak, they mean that the person they are talking about cannot understand words, and can never use words to communicate.

This is wrong.

When people think that we cannot understand words, they do not try to help us communicate. They do not give us access to AAC.

#### **What do we use instead?**

We say **people who cannot rely on speech to be understood**.

Some people, especially in the autistic community, use the word **nonspeaking**.

When CommunicationFIRST is talking about autistic people who cannot use speech, we say **nonspeaking**.

But some people in our community, including some autistic people, can speak sometimes, or identify as speaking for a different reason.

Because of this, we do not use **nonspeaking** as a word for everyone in our community.



## 2. **Severe** or **profound**

These are negative words. They make people feel afraid or sad.

Describing us as **severe** or **profound** makes it hard to see us as friends, neighbors, or leaders.

But disabled people are not strange, scary, or hard to find. We are just people who might need support to live well.

### **What do we use instead?**

If it is important to talk about the person's support or access needs, we will describe those needs.

Or, we might say something like, "**They cannot use speech to be understood, but we haven't found AAC that works for them yet.**"



### 3. **Disorders, impairments, or deficits**

**Disorder** means a disease. **Impairment** means not being able to do something, or being able to do it less than other people. **Deficit** means not having something.

It is wrong to say that we have communication diseases. It is wrong to say that we cannot communicate, or that we have no communication.

**Disorder, impairment, and deficit** suggest that some kinds of communication are worse than others.

This is not true. All kinds of communication are good and important.

These words also forget an important truth: communication isn't something we **have**. It is something we **do together**.

When we communicate, we work together to share and understand what we have to say.

#### **What do we use instead?**

We might use more neutral words like **communication disability** or **condition**.

If you aren't sure what to say, describe how they communicate:  
“**They use AAC,**” or “**They gesture or look at what they need, but don't have the tools to communicate with words yet.**”



#### 4. **Complex communication needs**

These words try to explain that our communication needs are complicated, difficult, or hard.

It's true that many of us struggle to communicate. But that doesn't mean that what we **need** is hard.

What we **need** is to communicate with other people and be understood.

And every single human being needs that!

We feel that saying **complex communication needs** is a little bit like saying **special needs**.

We don't use those words, either.

These words don't really help people understand what we need. It just makes people afraid to try to get to know us.

##### **What do we use instead?**

We describe what someone needs.

We might say, "**She needs her letterboard,**" or "**They need time to type on their AAC device.**"



## 5. **Non-communicative**

Everyone communicates!

We might communicate by moving, pointing, looking, or making sounds.

The only way we can ever “have no communication” is if other people dismiss the ways we communicate.

Plus, it is just too easy to think of a **non-communicative** person as **never** being able to communicate, no matter what.

This idea means that some people who need AAC might never get it.

### **What do we use instead?**

We describe and respect the ways someone already communicates.

We might say, “**He doesn’t have language-based AAC yet, but he knows how to communicate what he wants in other ways.**”

We might say, “**They are learning this kind of AAC.**”



## 6. Behaviors

People move in different ways.

Some movement is on purpose. Some movement is not on purpose. Some movement is because of pain or emotions.

All of these movements happen for a reason.

No human being is just a bundle of behaviors.

When we call these movements **behaviors**, it gets harder to see the human behind the movement.

**Behaviors** become something to control, instead of something to understand, or something that we live with.

### What do we use instead?

We try to be specific about the movement, noise, or action.

We might say, “**She was pacing because she needed to go to another room**” or “**He yelled when he was in pain.**”



## 7. **Clients** or **consumers**

CommunicationFIRST is an organization led by people with disabilities.

These words might make sense for someone who helps people get AAC, but these words do not make sense for us.

### **What do we use instead?**

We might say **members of our community**.

We might use words that describe the people we are talking about, like **AAC users** or **people who cannot rely on speech alone to be heard and understood**.



## 8. **Communicative competence**

When we are learning how to use new AAC, it's important to know about the skills we already have and the skills we need more help with.

The ideas behind **communicative competence** can help with this.

**Communicative competence** is a framework. A framework is a way of looking at how related ideas work together.

The ideas behind this framework are used by some professionals to talk about our communication skills.

These **ideas** can be helpful, but we think that the way that these **words** are used is not always helpful.

It's too easy to use these words to say that someone is not good enough at communicating to be able to use AAC.

Using these words might mean that some people don't get access to the AAC they need.

### **What do we use instead?**

We don't have a good word for this idea yet.

We want to talk more about these ideas later.





## What else?

All people should be able to tell us the kinds of words **they** use for themselves, and why.

If you can't use speech to be understood, always or some of the time, you can take [this survey](#) to tell us more about how you feel about these words.

You can fill it out at any time. This survey will stay open permanently.

\* \* \*

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

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If you have questions about this guide or about the survey, you can email us at [info@communicationfirst.org](mailto:info@communicationfirst.org).