

a film by Marco Niemeijer

this is not about me

a story about growing up
non-speaking



A Toolkit for Educators of Students Who Cannot Rely on Speech to be Understood



Communication ***FIRST***

Because communication is a human right.

Primarily authored by nonspeaking autistic AAC users Cole Sorensen (B.S., Special Education) and Jordyn Zimmerman (M.Ed. pending). Available at www.thisisnotaboutme.film

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“Teachers were convinced that I would never be able to understand more than simple language.”

- Jordyn Zimmerman

Film Reflection and Discussion Questions

- What assumptions do others often make about students who can't speak?
- Why do you think Jordyn acted in a way that teachers found “challenging”? Why do you think Jordyn’s teachers felt challenged by her behaviors?
- Jordyn’s teacher described her as “one of the most challenging children I’ve ever worked with.” What can you take away from Jordyn’s story to remember when you’re working with students who are viewed as “challenging”?
- How do you think students like Jordyn, who haven’t been given access to language-based communication, can have a voice in their own IEP meetings?
- What steps can you take to ensure more students with speech-related disabilities gain access to augmentative and alternative communication (AAC) as early as possible?
- When Jordyn was attending Mentor High School, she traveled over an hour to be included with other students her age and engaged in stimulating material. What steps can you take to make sure students have meaningful opportunities to learn in their own communities?
- What will you do differently as a result of watching this documentary?



Basics and Terminology

What is Alternative and Augmentative Communication, or AAC?

AAC is any tool or strategy other than speech that someone may use to communicate when they cannot speak with their mouth. AAC can include typing or selecting pictures on a tablet or phone, pointing or blinking at a paper board with symbols or letters on it, body language, facial expressions, gestures, and many other strategies. Some people use some signing or finger spelling as an AAC strategy, although sign language itself is considered a distinct language and not a form of AAC.

A robust, language-based system is one that can be used to communicate a wide variety of messages. The system should be language-based, not just based on body language or gesture. Robust AAC either includes the alphabet to allow the user to spell out any potential thought, or a large amount of vocabulary with all the parts of speech represented with access to the alphabet as well. Here is a [further explanation](#) of what makes an AAC system robust.

Who May Need AAC?

People may need AAC for a variety of reasons. Students who may need AAC may have an IEP disability category of Autism Spectrum Disorder (ASD), Intellectual Disability (ID), Orthopedic Impairment, Multiple Disabilities (MD), Speech/Language Impairment (SLI), Other Health Impairment (OHI), Traumatic Brain Injury (TBI), or Developmental Delay (DD).

“The assumption was that I had no understanding and professionals saw my behavior as being unintelligent. They focused on my behavior and made the assumption that I would not be able to express myself with any form of language.”

- Jordyn Zimmerman



According to a recent study, approximately [1 in 89](#) students in K-12 settings in the United States do not use speech or have “highly unintelligible speech” and need access to robust, language-based AAC. However, only about 20 percent currently have such access (Binger et al. 2021).

“Nonspeaking” or “Nonverbal”?

People who do not speak have historically been labeled “nonverbal.” Because the word “verbal” means “relating to words,” not “speech,” that term isn’t usually an accurate way to describe someone who cannot speak.

Using the term “nonverbal” can also be **harmful** because it suggests that the person has no language and thus can’t benefit from language-based AAC, instead of simply conveying that they cannot speak.

Because speech is a motor function and language is a cognitive function, there is no reason to assume that a hearing person who cannot speak has a language disability. The way a person with a motor control disability acts or moves their body after hearing language cannot tell you how much language they actually understand.

[No one is too disabled to benefit from AAC.](#) People who cannot speak almost always can understand language. Given the right supports, they can almost always learn to express themselves using some form of language-based AAC.

Many autistic people who do not speak [prefer the term “nonspeaking.”](#) You could also describe the person as someone who needs or uses AAC, someone who cannot rely on speech to be understood, or someone with little to no understandable speech.

As with identity-first or person-first terminology or pronouns, it’s best to ask the person themselves what terms they prefer.

What Are Student Rights and School Responsibilities Regarding AAC in the US?

In the United States, the rights of students with disabilities to access communication tools and supports are protected under several laws, including the Americans with Disabilities Act (ADA), Section 504 of the Rehabilitation Act, and the Individuals with Disabilities Education Act (IDEA).



Here is an [official guidance document](#) from the US Department of Education and US Department of Justice explaining the rights of students under these laws to access and be supported with communication tools and supports in school settings.

- The ADA's effective communication regulations at [28 C.F.R. § 35.160](#) require public school districts in the US to provide access to a student's preferred AAC in a timely manner if necessary to ensure equal access and equal opportunity to participate.
- Under the IDEA, students with an IEP who have difficulty communicating and who do not yet have AAC must be evaluated and provided with assistive technology devices and services ([34 C.F.R. § 300.105](#)).
- Any assistive technology device or service that is determined to be necessary must be made available to the student.
- Students [generally have the right](#) to bring school-purchased devices home with them.
- The IDEA requires that parents, teachers, and other employees working with the student [be trained](#) in how to support the student to use AAC to communicate. Supporting a student to learn to use an AAC system fluently often takes years and requires a collaborative team approach.

A district-wide AAC Work Group can be beneficial to supporting all students with expressive communication support needs, and may include Assistive Technology team staff, speech-language pathologists, occupational therapists, general education teachers, special education teachers, central office administrators, parents, and students.

Best Practices

Introduce AAC as soon as possible!

Robust, language-based AAC should be introduced as soon as a child is suspected to have a speech delay, ideally in early intervention programs *before* they start school. The student should be provided with intensive supports to learn how to use AAC so that they are as fluent as possible by kindergarten.



AAC does not hinder speech development, and in fact there is [research that indicates it supports it](#), so teams should never wait to introduce AAC.

AAC should never be considered a “last resort,” and [should be offered as an option](#) to all students who may benefit.

Never give an IQ test to someone who cannot rely on speech to be understood!

IQ tests are not valid for someone who cannot rely on speech to be understood. Do not administer an IQ test unless the student is already able to fluently use a robust, language-based form of AAC, and can use that AAC to take the test, as required by the IDEA ([34 C.F.R. § 300.304\(c\)](#)).

Why? The use of IQ tests for people with speech and other motor disabilities is not evidence-based. All currently existing, standardized measures of cognitive assessment require the test-taker to either answer a question using speech, to point to an answer, or to hold a pencil to mark an answer. Most people who cannot rely on speech to be understood have [other motor impairments](#) that prevent them from being able to direct their bodies to accurately point and use a pencil.

“My brain always instructs me to do one thing, but for some reason, my body does something else. If I could control these things, then I would.”

- Jordyn Zimmerman

“When I was in middle school, I vividly remember hearing about my IQ test that was in the sixties. I don’t know why that sticks out so much. And I now believe these tests are a terrible measure. I really don’t know what professionals think my worth would be.”

- Jordyn Zimmerman

Even “nonverbal” IQ tests require that the test-taker have reliable motor function to take the test. (In other words, “nonverbal” tests are *not* designed for, and are inappropriate for, most “nonverbal” people.)

Administering IQ tests to students who need but do not have access to robust AAC can cause harm. Doing so will likely cause the student to be inaccurately labeled as having an intellectual disability.



Once a student is labeled as having an intellectual disability, that label often causes others to stop trying to give the student access to robust language-based AAC. Special educational methods that may benefit people with intellectual disabilities such as plain language and pictures may not be appropriate. Nobody with or without an intellectual disability should be segregated or denied access to age-appropriate education and literacy instruction.

“[My mom] was repeatedly told that I would not be successful with AAC at the time. There was such a focus on my behaviors that it was almost a prerequisite in a way, which just shouldn’t be.”

- Jordyn Zimmerman

No prerequisites for access to AAC!

Providing someone access to AAC should never depend on the person acting a certain way, [meeting certain targets](#), or [mastering a simpler system first](#). Students should not have to prove they can use a system with very limited vocabulary before “earning” access to a robust system.

Honor and respect all communication.

Remember that a nonspeaking student has already gone through a lifetime of being unheard and not understood. This is a recipe for complex trauma (also known as developmental trauma), and students who need AAC should be treated with trauma-informed principles and practices.

Don’t add to their trauma by refusing to acknowledge communication attempts unless they are expressed in a certain way.

Students may use their AAC in different ways, like pressing buttons seemingly at random or hitting the same button over and over again. Exploring and experimenting with the AAC system is a part of the learning process.

Never take away or prevent someone from communicating with their communication tools and supports!

Just as you wouldn’t duct-tape a speaking student’s mouth shut, you [should never, ever take away someone’s AAC](#), especially as punishment.



“I remember in 4th and 5th grade, my aide would just talk about me to other people in front of me.”

- Jordyn Zimmerman

Communication is not a privilege; it’s a right. If a student is using their AAC system in a way you think is inappropriate or distracting, you can turn down the volume or ask them to wait their turn. Do not remove their voice altogether.

Don’t talk about students in front of them without involving them in the conversation.

Even when you are unsure what a student understands, presume that students are [able to understand you](#) unless they tell you otherwise. Speak to students in age-appropriate ways. Do not use “baby talk.”

Talk to them, not about them. Include them in conversations and give them opportunities to respond in a variety of ways. Even if students do not yet have access to a system of communication that’s reliably understood by others, direct questions toward them and allow them to respond however they best can.

Restraint and Seclusion

Students who aren’t given adequate communication support end up communicating through other means. Sometimes people communicate non-verbally through behavior. However, not all behavior is purposeful or intended to be communication. Problem behavior is best addressed by giving people a better way to be understood and get their needs met. Restraint and seclusion are never appropriate responses.

[Restraint and seclusion cause trauma](#), and can lead to significant injury to both students and teachers. It only increases the student’s distress. This compounds the problems.

“The paperwork on Jordyn, it described a child who was extremely low-functioning, unwilling to learn, extremely aggressive. But I began to notice that every time she had an aggressive episode, every time that episode was over, it all came down to ... there was some kind of breakdown in communication.”

- Former principal Mrs. LaPaglia



CommunicationFIRST's short film [LISTEN](#) (2021) and [accompanying toolkit](#) touch on the topic of restraint.

Comprehensive Literacy Instruction

Students need instruction in all aspects of literacy, including phonics, sight word recognition, vocabulary, comprehension, and writing. Many [evidence-based strategies](#) exist to teach literacy skills to nonspeaking students.

Segregation versus Inclusion

Historically, AAC users have been disproportionately likely to spend most of the school day in a segregated classroom, but that does not need to be the case.

Four decades of research shows that even students with the most significant support needs, even those with significant intellectual disabilities, experience far greater educational, social, and other gains when supported to learn in a fully [inclusive environment](#), alongside nondisabled students. Students' likelihood of success depends on the [quality of supports](#) given to them. Segregated classrooms are not only stigmatizing, but convey low expectations and are more likely to be [less safe settings](#), where restraint, seclusion, and abuse occur more frequently.

**“If people get the sense that you are giving up on them,
their natural response may be to not even try.”**

- Jordyn Zimmerman

Additional Resources

- [Communication Bill of Rights](#)
- [Everybody Communicates: Toolkit for Accessing Communication Assessments, Funding, and Accommodations](#) (Office of Developmental Primary Care)
- [AAC Devices: What They Are and How You Can Get One for Your Autistic Child](#) (Not an Autism Mom)
- [People Like Me](#) (short film by Marrok Sedgwick)
- Note: Some of Jordyn's quotations are taken from the documentary; others are from a CommunicationFIRST video to be released in 2022.