

Because Communication Is a Human Right

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CommunicationFIRST
Because communication is a human right.

Objectives



1. Learn about us and why communication should always be the first priority in your advocacy.
2. Reflect on best practices and students' rights to communicate in US schools.
3. Apply new advocacy tips as you engage in your work.

About us

About CommunicationFIRST



The only civil rights organization led by and for the 5 million children and adults in the US who cannot rely on speech alone to be heard and understood

- Cross-disability
- Disability-led (<https://communicationfirst.org/aboutus/>)
- Launched October 2019

Mission



Advance the rights, autonomy, opportunity, and human dignity of our historically marginalized population through three key strategies:

- (1) public education and engagement
- (2) policy and practice reform
- (3) direct advocacy

Who We Are



Over 5 million in US with speech-related disabilities

- **Congenital and Developmental**

Apraxia, autism, cerebral palsy, Down syndrome, rare genetic syndromes, Tourette syndrome

- **Acquired**

ALS, aphasia, dementia, locked-in syndrome, multiple sclerosis, muscular dystrophies, Parkinson's, traumatic brain injuries



Communication is a basic human need, a basic human right. And more than this, it is a basic human power.

”

BOB WILLIAMS



CommunicationFIRST

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Our Work

- Change the **social narrative** and **public understanding**
- Reduce barriers and ensure **equal opportunity** to meaningfully participate in all aspects of life and community



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Our Work



- Ensure access to **robust expressive communication tools and supports**
- Improve access to **health care and informed consent practices**
- Improve **self-determination** and alternatives to guardianship
- Ensure **equal access to justice**

Our Work



- COVID Communication Rights Toolkit
- COVID **hospital no-visitor policies**
- Educational toolkit on equal access to **remote schooling**
- **Restraint and seclusion in schools**
- Improving **data equity (AAC Counts)**

See us. Hear us.

Jordyn Zimmerman



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What is Communication?

What is Communication?



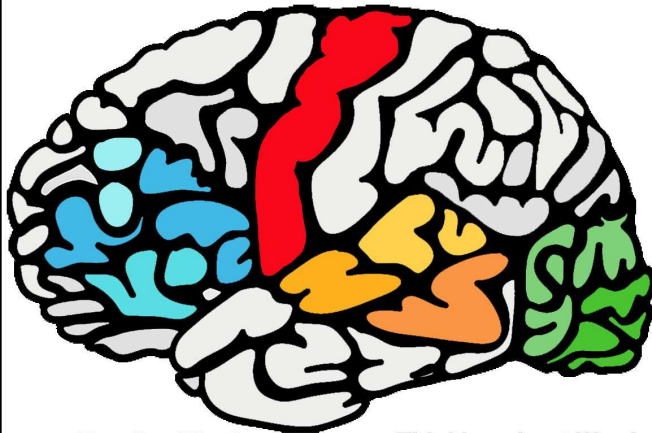
- Receiving and perceiving information (seeing, reading, hearing, listening, touching/feeling) (receptive)
- Processing and understanding information (receptive, cognitive)
- Asking questions to clarify understanding (expressive)
- Expressing decisions, preferences, desires, feelings (expressive)
 - Including informed consent, voting, signatures, transactions, emojis
 - Also pointing, gestures, facial expressions, eye gaze, laughing
- Communication also includes information your body may communicate about your physical or emotional state, like signs of pain, nausea, anxiety, fear (expressive)





Not Just Speech, Not Just Language



- Think broadly about communication in your advocacy – and all the supports and accommodations that may be needed to achieve communication access and equity
- **Speech is not the same thing as language**
 - Speech is a **motor** function
 - Language is a **cognitive** function
- There is no anatomical basis to assume that someone who cannot speak also cannot understand or express language

WORDS AND THE BRAIN



- | | |
|---|---|
|  Reading Words
(Occipital Lobe -
Vision) |  Thinking about Words
(Broca's Area -
Language production) |
|  Hearing Words
(Wernicke's Area -
Language
Comprehension) |  Saying Words
(Motor cortex) |
- Linda Robinson © 2010

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IQ Tests



- IQ tests are not valid or evidence-based for someone who cannot rely on speech to be understood
 - All standardized psychometric assessments of intelligence assume either normal speech, normal hand control, or both
- Do not administer an IQ test to a student unless they are 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))
- Inappropriately administered IQ tests are often used to deny access to AAC and force segregation

Language Has Power



- *non-communicative*
 - inaccurate
- *nonverbal*
 - inaccurate: speech ≠ language (the root “verb” connotes language)
 - self-fulfilling prophecy
 - dehumanizing and othering
- *severe*
 - dehumanizing and othering

What Do We Use Instead?



We try to be as descriptive, broad, and inclusive as possible:

- People who cannot rely on speech alone to be heard and understood
- People with expressive communication disabilities
- People with speech-related disabilities
- People who need and use AAC
- AAC users
- Note that “nonspeaking” is often preferred by autistics, but not by everyone in our community, so we only use this term when specifically referring to autistic people
- Stay tuned for our forthcoming “Words We Use” document

Importance of Effective Communication



- Hard to overstate
- Recognized as a fundamental human right, basis for all other human rights
- **Necessary for**
 - Education
 - Emotional well-being, mental health
 - Access to medical health care
 - Citizenship, voting
 - Social relationships and community integration
 - Safety, access to justice, reporting, testifying, due process
 - Self-determination
 - Meaningful employment

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Congress Agrees



“Individuals with disabilities continually encounter various forms of discrimination, including **outright intentional exclusion**, ... **communication barriers**, ... **segregation**, and relegation to lesser services, programs, activities, benefits, jobs, or other opportunities”

Americans with Disabilities Act, 42 U.S.C. § 12101(a)(5)

“**Speaking**” and “**communicating**” are “**major life activities**” on the same level as “**breathing**” and “**thinking**”

Americans with Disabilities Act, 42 U.S.C. § 12102(2)(A)

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Importance of Effective Communication



- Effective communication strategies are often denied when the person is presumed to lack “communicative intent” or the capacity to understand language
 - **vicious cycle** (how can you prove otherwise without effective communication tools?)
- The costs: years of missed education, isolation, depression, “acting out” in frustration (often leading to restraint and seclusion), opportunities foreclosed, trauma

What is AAC?

What Is AAC?



Augmentative and Alternative Communication is **anything other than speech that can help a person be understood:**

- Gestures, eye gaze, pointing, facial expressions, sounds, body positioning, laughing, smiling
- Pointing or looking at pictures, icons (low tech, high tech)
- **Robust, language-based AAC** (no, low, high tech)
 - Writing, signing, typing, texting, pointing to letters and words that can be combined to communicate anything
 - Someone familiar with a person's speech repeating what they are saying (revoicer)

Most people use **many** of these! And the need may be intermittent.

Dispelling Myths



- AAC does not hinder speech development, and in fact there is research that indicates it supports it
- AAC should never be considered a “last resort,” and should be offered as an option to everyone who may benefit



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Best Practices



- Start in early intervention!
- Give access to the entire alphabet and teach typing; don't control and manipulate a person with a disability by limiting their vocabulary
- Everyone is different - supports must be individualized
- AAC must be available 24 hours a day, in all settings
- Interpreters and communication support people need to be trained and effective!
- Assume a trauma history
- Do not assume a hearing or language disability

Choosing AAC



- Open-ended communication (e.g., the alphabet) is better than preselected word/phrase options
- Training is essential! This is true both for the individual and the supporters. It nearly always takes an AAC user years to learn to use robust AAC effectively/fluenty.
- Keep in mind that several different communication methods may be needed for different situations (just like for nondisabled people do!)

Communication Rights at School

AAC Users Interview Jordyn Zimmerman November 10, 2021 - 7:00 pm ET



WEBINAR: <https://communicationfirst.org/aac-users-interview-jordyn-zimmerman/>

FILM: <https://thisisnotaboutme.film/>

TOOLKIT:

<https://thisisnotaboutme.film/wp-content/uploads/2021/10/CommunicationFirst-This-Is-Not-About-Me-Toolkit.pdf>

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Communication Rights at School



1. Individuals with Disabilities Education Act (IDEA)
2. Section 504 of the Rehabilitation Act
3. Americans with Disabilities Act (ADA)

Joint guidance from the US Department of Justice and Education has made clear that public schools are **required to comply with all three laws** when it comes to students with communication (vision, hearing, and speech) disabilities.

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ADA vs. IDEA



Very different frameworks

- **IDEA** is mainly about providing services
 - PK-12 and transition settings
 - Teaching student how to use AAC
 - Access to AAC as accommodation
- **ADA** and **504** are about rights, access, equity, opportunity, and anti-discrimination
 - Most public and private settings (including schools, colleges, universities, residential, recreational settings)
 - Access to AAC as accommodation

ADA vs. IDEA



IDEA

- Free and *appropriate* education
- Least restrictive environment ... to the maximum extent *appropriate*
- Related services that are required to assist [SWD] to *benefit from* special education
- *Consider* the communication needs of the child
- *Consider* whether the child needs assistive technology devices and services

ADA

- *Equal* access and opportunity
- *Most* integrated setting
- Accommodations
- Anti-discrimination

ADA's Additional Rights

- Effective communication
- Service animals
- Physical accessibility
- Anti-retaliation
- Monetary damages

IDEA



Schools must “ensure that **assistive technology devices or assistive technology services**, or both, ... are made available to a child with a disability **if required as a part of** the child’s (1) special education ...; (2) related services ...; or (3) supplementary aids and services ...” 34 C.F.R. § 300.105(a)

(circular?)

IDEA



- AT Device: “any item, piece of equipment, or product system, whether acquired commercially off the shelf, **modified, or customized**, that is used to **increase, maintain, or improve functional capabilities** of a child with a disability.” 20 U.S.C. § 1401(1)
- AT Service: includes selection, acquisition, **use, training** professionals, the child, the family (“where appropriate”), and employers, customizing, repairing, replacing AT device. 20 U.S.C. § 1401(2)

ADA



- Public entity “shall ... **ensure** that communications [with PWD] ... are **as effective as** communication with others.” 28 C.F.R. § 35.160(a)(1)
- “Shall furnish appropriate **auxiliary aids and services** to afford [PWD] an **equal opportunity** to participate in, and enjoy the benefits of a service, program, or activity of a public entity.” 28 C.F.R. § 35.160(b)(1)
- “Shall **give primary consideration** to the requests of individuals with disabilities.” 28 C.F.R. § 35.160(b)(2)

ADA



Auxiliary aids and services

- Must “consider the **method of communication used by the individual, the nature, length, and complexity** of the communication involved, and the **context** in which the communication is taking place.” 28 C.F.R. § 35.160(b)(2)
- Must be “**as effective as** communication with others” 28 C.F.R. § 35.160(a)(1)

ADA



“The public entity **must provide an opportunity** for individuals with disabilities **to request** the auxiliary aids and services **of their choice** ... [and] **shall honor the choice** unless it can demonstrate that another **effective** means of communication exists or that use of the means chosen would not be required under § 35.164.” 28 C.F.R. Part 35, Appendix A

ADA



- Request can only be denied by proving *in writing* that it would cause either a “fundamental alteration” or “undue burden.” 28 C.F.R. § 35.164
 - Burden is assessed compared to the school district’s entire operating budget
 - Even if denying, still must “take any other action” to “ensure that ... individuals with disabilities receive the benefits or services provided by the public entity”

Federal Guidance



DOE-DOJ FAQs on Effective Communication for Students with Hearing, Vision, or Speech Disabilities in Public Elementary and Secondary Schools (Nov. 12, 2014)

- Confirms that public schools must adhere to **both** IDEA and ADA and that different standards apply
- The IDEA doesn't trump the ADA
- Student choice is key

Federal Guidance



- “When the school district knows that a student needs assistance with communication because, for example, he or she has a hearing, vision, or speech disability, the school district also has an **affirmative obligation** to provide effective communication under Title II, **whether or not a parent requests** specific auxiliary aids and services under Title II.” (p. 17)

Statutes in Summary



- Schools have to comply with *both* the ADA and IDEA
- ADA creates very different rights and imposes stronger substantive requirements and standards on schools than the IDEA
 - Especially on effective communication and inclusion

Advocating for
Communication at School

What is *Effective* Communication?



Practically

- Does the AAC device, system, or method:
 - Give the user access to entire alphabet, unlimited vocabulary, punctuation?
 - Enable the user to produce original, unlimited, and open-ended output?
 - Allow the user to conjugate verbs? Write poetry or an opera? Take AP Physics or Calculus? Engage in word-play? Tutor a struggling classmate?

Ineffective Communication Systems?



- Systems that **limit potential expressive output**
 - *Requesting* systems ≠ communication systems
 - Assume user has *intellectual* or *language* impairment
 - Rather than a *speech* impairment
 - Possible output is chosen by a nondisabled person
- Systems that are provided with **inadequate training and support** for user and support people
- Not meeting the student's individual needs
 - ASL for someone with motor control impairments?

Advocacy Tips



- Think about all the student's disabilities that necessitate the requested supports
 - ADHD? Apraxia? Cortical visual impairment? Anxiety? Sensory impairments (visual, auditory, proprioception, interoception, vestibular)? Insomnia? GI issues? OCD? Epilepsy?
 - Autism? Given its heterogeneity and the fact that the diagnosis tells you nothing specific about the student's actual support needs, consider omitting. It rarely provides any benefit to the student and usually leads to low expectations (or fear!).

Advocacy Tips



- Detail the individualized supports the student needs to access school and to communicate effectively throughout the entire day
 - The device or app itself is often less than 5% of it!
 - The full-time presence of an adult (and availability of a backup) who is trusted and has been trained to support the student's individual disability-related support needs, including their communication support needs

Communication Support People



- Trained to support the disabled student's individual needs
 - Training should include not just their form of language-based AAC but also how they communicate using body language
 - What does it mean when he paces back and forth?
 - How can you tell when she is in pain?
 - How do you know when he is hungry or thirsty?
- Conscientious about trauma, safety, power differentials
- Advocates (e.g., to ensure accommodations are provided)

Sample Accommodations



- Trusted and trained communication support person/paraprofessional
- Training for backup personnel and other adults
- Training for fellow students/classmates
- Reduced workload/homework
- Additional time to complete assignments, worksheets
 - No grading on assignments and tests until fully accommodated
- Team planning time (to adapt curricular materials and lessons if necessary)
- Modified/flexible school day (no attendance taken)
- Attending class remotely via video link (Zoom, Skype, Teams, GoogleHangouts)
- Read-aloud
- Large font
- Open captions on all video materials
- Daily school-home communication log

Sample Testing Accommodations



- Trained communication support person + scribe
- Extended time; over several days in short spurts
- Quiet room, non-fluorescent lighting, larger table
- Seating
- Paper-based vs. computer (latter often involves fewer questions)
- Read-aloud
- Fidgets

Refusing IQ Tests



- Ask the IEP team what information they will get from the assessment that they think is necessary to have to inform eligibility or IEP goals
- Arguments
 - They are not evidence-based for students who cannot speak or move their hands reliably
 - Be open to a test that will produce accurate results
 - They are very stressful for the student
 - They usually pull the student out of instructional time to administer, which is harmful to the student
 - Administering such evaluations is expensive and time consuming
 - Without effective AAC, the test will inevitably result in an artificially low IQ score, which often is used as a weapon to segregate the student and to refuse to give them access to robust, language-based AAC

IDEA Language on Assessments



- Evaluation must “be provided and administered **in the child’s native language or mode of communication.**” 20 U.S.C. § 1412(a)(6)(B)
- Assessment must be “provided and administered in the language **and form most likely to yield accurate information on what the child knows and can do academically**, developmentally, and functionally, unless it is not feasible to so provide or administer.” 20 U.S.C. § 1414(b)(3)(A)

A Note on Inclusion



Why Question Segregated or “Self-Contained” Settings?

- Separate is almost always unequal
 - Unequal curricula
 - Unequal facilities
 - Unequal opportunities
- Segregated settings for SWD are not evidence-based!
 - **Not a single study demonstrates the benefits of separate placements!**
- They are *less safe*: No witnesses to report abuse

Why Inclusion?



The most fundamental reason to advocate for an inclusive placement is because it's **safer**. Because our kids need to be surrounded by **verbal witnesses**. Because our **girls are 8 times more likely to be sexually assaulted** than girls without a developmental disability. Because the greater the speech and communication disability, **the greater the risk of abuse**. Our **boys are 5 times more likely to be assaulted** than boys without disability. 49% of the assaults against people with developmental disabilities are from a **paid support staff**. The 3rd most common abuser is other people with disabilities who are "clustered with their victims in a services setting." **Our kids need to be surrounded by people who do not have power over them. People who can report abuse or neglect. People who can learn to listen to them and can learn to speak up for them.** When a mark appears on our child's body, **we need to be able to ask the other kids what happened. Our kids need the safety of 30 pairs of classmate eyes on them.**

- Erin Sheldon, February 12, 2019

Inclusion for AAC Users?



Three Dan Habib Videos

- Thasya: <https://bit.ly/2FrQWjv>
- Axel: <https://bit.ly/2TigiYt>
- Samuel: <https://bit.ly/2umgkko>



Advocacy Summary



- Request AAC evaluations early and often and for every student who has any expressive communication difficulties
- Training for aides, teachers, and parents is critical
- Raise expectations & challenge assumptions
 - Remember speech ≠ language
 - Decline IQ testing as not evidence-based
- Literacy and language-based communication are perhaps the most critical “life skills”
- Inclusion, inclusion, inclusion!

Resources



- “Ask Me, I’m An AAC User!” Facebook group
- “Everyone Communicates: Toolkit for Accessing Communication Assessments, Funding, and Accommodations”:
<https://odpc.ucsf.edu/communications-paper>
- Erin Sheldon & Karen Erickson (2020), “Why Literacy Matters for People with Significant Disabilities” (Google for two-episode podcast interview) and article:
<https://www.atia.org/wp-content/uploads/2020/06/ATOB-V14-A9-SheldonErickson.pdf>
- Erin Sheldon, Safeguards for AAC users: vulnerability, autonomy, and being heard (<https://presenters.aacconference.com/videos/UVRReIFURTU=>)

Resources (2)



- CommunicationFIRST Communication Equity Call to Action: <https://communicationfirst.org/communication-equity-call-to-action/>
- Recommended short films featuring AAC users
 - See Us, Hear Us - Jordyn Zimmerman: <https://communicationfirst.org/birthday>
 - This Is Not About Me: <https://thisisnotaboutme.film/>
 - LISTEN: <https://communicationfirst.org/LISTEN/>
 - My Disability Roadmap: <https://likerightnowfilms.com/film/3356/My-Disability-Roadmap>

Resources (3)



- Strategies for Supporting AAC Use in Inclusive General Education Classrooms: <https://ici.umn.edu/products/impact/312/Supporting-AAC-Use/#Supporting-AAC-Use>
- US Department of Education and US Department of Justice FAQs on Effective Communication Obligations in PK-12 Schools (November 2014): https://www.ada.gov/doe_doj_eff_comm/doe_doj_eff_comm_faqs.pdf

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 - <https://www.bonfire.com/store/communicationfirst/>



Access.
Opportunity.
Justice.



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QUESTIONS?

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