THE LINKCENTER
Bridging I/DD and Mental Health Systems

CommunicationFIRST
Because communication is a human right.

Communicating in Times of Stress

A resource for lifeline workers and other allies

In moments of intense stress—when speaking up and being heard may be more important than ever—some people lose the ability to communicate in the ways they usually do.

Losing speech and/or language in times of stress can happen to anyone, regardless of diagnosis, disability, or the way they typically communicate, i.e., whether the person uses natural speech or relies on augmentative and alternative communication (AAC) tools and supports. However, stress-induced loss of speech or language is more common for people with certain disabilities, such as autism, intellectual disability, acquired brain injury, post-traumatic stress disorder, situational mutism, anxiety, schizophrenia, dementia, aphasia, and Parkinson's disease, among others.[1]

The way occasional speech or language loss is experienced depends on the cause, the circumstances, the individual, their disability, and other factors like environment, pain, medication, or cultural background. Here are just a few examples:

- They feel like the part of their brain that translates thoughts to words has stopped working.
- They feel like they need more time to process information than they usually do.
- Their words or thoughts are feeling "jammed" or "stuck," or they feel like their whole mind has suddenly gone blank.
- They feel like their thoughts are going in circles, and they are having trouble with new or different words and ideas. You may know this as perseveration.
- Their body feels too cold or too heavy to move or control, or they feel frozen; they can't move their mouth or make noise from their throat, even if they can move other parts of their body. You may know this as catatonia.

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[1] *See, e.g.*, Zisk, A. H., & Dalton, E. (2019). Augmentative and alternative communication for speaking autistic adults: Overview and recommendations. *Autism in Adulthood, 1*(2), pp. 93–100. https://doi.org/10.1089%2Faut.2018.0007; Sparrow, M. (2017). *Coping with a crisis when you have unreliable or intermittent speech* [Blog post]. Thinking Person's Guide to Autism. https://thinkingautismguide.com/2017/11/coping-with-crisis-intermittent-speech.html; The Defense Health Board, the Defense and Veterans Brain Injury Center & Department of Veterans Affairs. (2012). *Communication effects after brain injury* [Blog post]. Brainline. https://www.brainline.org/article/communication-effects-after-brain-injury; Viana, A. G., Beidel, D. C., & Rabian, B. (2009). Selective mutism: A review and integration of the last 15 years. *Clinical Psychology Review, 29*(1), pp. 57–67. https://doi.org/10.1016/j.cpr.2008.09.009; van der Heide, A., Speckens, A. E. M., Meinders, M. J., Rosenthal, L. S., Bloem, B. R., & Helmich, R. C. (2021). Stress and mindfulness in Parkinson's disease - a survey in 5000 patients. *npj Parkinson's Disease, 7*(7). https://doi.org/10.1038%2Fs41531-020-00152-9.

December 2024

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Don't assume that someone has a particular condition or is experiencing a particular phenomenon (such as perseveration or catatonia) just because they describe their symptoms in a particular way. Take the person at their word (if they can communicate with words) and try to see the world through their eyes. Focus on accommodating their disability, making communication possible, and helping them through the stressor; avoid prioritizing or pathologizing the speech/language loss itself. Helping them to regain their usual communication should not be the *only* goal of your interaction.

How can I help a person who is having trouble communicating?

Occasional speech or language loss happens most often when an individual is stressed, upset, in pain, dysregulated, or in a difficult or dangerous situation. Unfortunately, struggling to communicate as usual can make navigating those circumstances much harder, or even impossible. Whether you're talking someone through an acute mental health crisis, collaborating on a transition plan at the end of an inpatient stay, or calming someone down after an accident, learning about occasional speech or language loss means you'll be better prepared to offer meaningful support to the members of your community who experience it.

- **Offer your unconditional support.** Make sure the individual knows that they don't have to speak with their mouth in order to be heard, understood, respected, and cared about. Never force someone to speak if they are having trouble, and stand up for them if someone else is trying to coerce or pressure them.

  Some people may not realize right away that they're struggling. If you think someone is having trouble communicating the way they usually do, ask about it. For example: "Would it be easier for you to type, or tell me what you mean in another way?" That said, some people who speak slowly or with effort may still prefer to use speech; likewise, someone typing slowly and with effort may still wish to type. Always honor their choice.

- **Sometimes the answer is as simple as patience, peace, and quiet.** Encourage the person to take it slow, and match their pace. Be patient, and recognize that it may take much longer to get words out in a way other than speech. Don't speak over them, including while they're typing or otherwise composing their message: wait for them to finish their words before you share yours. Don't talk to them like they don't understand or like they can't hear you. And remember that asking lots of questions can be overwhelming, even if you mean well. Take it one step at a time, and offer the person plenty of space and time to respond in full.

- **You might need to get creative to find a way for the person to communicate effectively.** Stress can change the access some people have to speech, language, and thought, and even if it's happened to them before, they may not necessarily have a solution when they reach you. Depending on the individual's abilities at the moment, you might consider: switching from a phone call to a text-based conversation; encouraging someone to supplement or replace their typed words with emojis if typing is challenging; or offering different methods of responding, like numbered options ("Can you tell me about the sounds around you? Are they (1) too loud? (2) too quiet? or (3) just fine?") or physical responses ("Nod for yes, shake your head for no, or shrug for I don't know," or "Blink once for yes, twice for no, and three times for I don't know"). When relevant, always give people an option for "something else" so they can still respond even if none of your options fit. For other strategies for enabling effective communication, see the end of this document.

- **Never move on until you understand.** If you can't understand someone's speech or language, don't pretend that you can. This pretense is usually obvious (and painful). Instead, ask clarifying questions and use the principles of active listening, using phrases like, "It sounds like you're saying…" or "So what I'm hearing is…" Don't correct grammar or spelling. If you're not sure you understand, rephrase what was said and ask if you have it right.

  Many people living with disabilities that affect the way they think, feel, and/or express themselves—such as mental illness, intellectual or developmental disability, neurodivergence, brain injury, aphasia, or something else—are acutely sensitive to the pain and isolation of being misunderstood, and many have dealt with it all their lives. Make it clear to the individual that what they have to say matters to you, and that you're willing to work to understand them.

- **Help them use the coping skills they already have.** People living with mental illness often have a few tricks up their sleeve already, but in moments of intense stress, they may need help to remember or figure out what those things are. The first step is often making the person more physically comfortable and improving their sensory environment. Ask what helps and offer examples, like a darker room, music, a screen (like an iPad), total silence, deep pressure (like a weighted blanket, squeezing their own hands, or giving themselves a big hug), or being near an animal. Might they need to take care of body needs like food, water, or the bathroom? Do they need medication for pain or anxiety? Help them find something that will make them feel even a tiny bit better to be in their body. Some individuals may also have a crisis plan, where things like this are already written down.

- **Treat them with respect.** Whether or not someone has access to speech and/or language, they always have feelings, thoughts, hopes, dreams, ideas, goals, and histories. Treat them as people, with all the rights that entails.[2] Presume competence: never treat them like children, unless they are children (but feel free to ask if using plain language would be helpful).[3] Value them and their lives as important and worthwhile.

What is AAC, and how can it help?

AAC stands for Augmentative and Alternative Communication, and it's an umbrella term for many different strategies and tools that people use to communicate when they can't use speech. People might use AAC all of the time, most of the time, or episodically, such as when they're under stress.

Some people who usually have access to speech may believe that they don't need AAC or don't have the right to use it, but the truth is that **AAC is for anyone and everyone who needs it, no matter when, why, or how often they can't rely on speech.**

Everyone communicates without speech sometimes. Pointing and gesturing is AAC. Making facial expressions is AAC. Typing on a keyboard or a phone is AAC. Using emojis is AAC. 😀 When people aren't able to rely on speech alone to be heard and understood, specific tools or supports that meet their specific needs may be needed to allow them to communicate effectively. Some of these may be new to you, and may even be new to the individual you're working with, depending on their past experience with AAC.

Using AAC during episodes of speech or language loss can reduce stress and make it possible to communicate effectively, but it's usually not a good idea to introduce a new form of AAC when an individual is already stressed. When helping someone find communication solutions, ask them what they're familiar with: if they've never used a letterboard before, a crisis probably isn't a good time to introduce it, but using emojis may be something they feel comfortable with.

AAC options include:

- Typing words letter-by-letter on a computer, a tablet, or a smartphone

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[2] Brady, N. C., Bruce, S., Goldman, A., Erickson, K., Mineo, B., Ogletree, B. T., Paul, D., Romski, M., Sevcik, R., Siegel, E., Schoonover, J., Snell, M., Sylvester, L., & Wilkinson, K. (2016). Communication services and supports for individuals with severe disabilities: Guidance for assessment and intervention. *American Journal on Intellectual Disabilities, 121*(2), pp. 121–138. https://www.asha.org/NJC/Communication-Bill-of-Rights/.

[3] Green Mountain Self-Advocates. (2019). *How to write using plain language.* https://gmsavt.org/resources/plain-language-webinar; Simple English Wikipedia. (n.d.) *How to write Simple English pages.* https://simple.wikipedia.org/wiki/Wikipedia:How_to_write_Simple_English_pages

- Using an AAC app or software with pre-programmed words and phrases
- Using emojis or pictures
- Drawing or writing by hand on a whiteboard, piece of paper, or tablet
- Using gestures or sign language
- Letterboards: a rectangle of cardboard or plastic with the letters of the alphabet, and sometimes common words like Yes and No, written on them

When helping people who deal with speech and language loss under stress to develop long-term stress management strategies and coping skills, encourage them to practice using different types of AAC in low-stress conditions. The more familiar a person is with a given AAC tool or support, the more easily they will be able to use it under stress.

That said, be aware that stress can make it difficult to communicate at all, and that includes communicating with AAC. Even full-time AAC users who have used the same AAC support every day for years may find themselves unable to use it if they're under enough stress. If someone is struggling to communicate with their usual methods of AAC, focus first on reducing immediate sources of stress and helping them to access sources of comfort. Just having a trusted person in the room can make communication possible for some people. Finally, consider trying a different form of AAC, such as pictures or emojis instead of typed words.

What else should I know?

- **Language matters.** Learn more about the language CommunicationFIRST uses and why when talking about people with speech-related disabilities in The Words We Use. Remember, though, that this community is diverse, and not everyone uses the same language to describe themselves. Listen to the person, and use the language they use for themselves.

- **Speech and language loss isn't anyone's fault.** When someone can't communicate the way they usually do, they might feel afraid, anxious, upset, guilty, frustrated, angry, or numb. Most people who lose speech or language have gotten reactions like anger, frustration, sadness, or even violence from the people around us. Struggling to communicate the way they normally do is never their fault, and they don't need to apologize for it. Remember, too, that an individual losing speech or language is not necessarily *your* fault, either. It's just one way that bodies and minds can respond to stress.

- **Using AAC isn't shameful, annoying, or childish.** Nobody should feel wrong, bad, or foolish for using AAC, whether they need it for every word or only when they're stressed. AAC is a way to access communication, just like wheelchairs are a way to access movement, and

captions are a way to access sound. AAC is normal, and it can be liberating. Dismissing AAC or treating it as worse or lesser than speech is ableism, plain and simple.

- **Chronic stress—for example, as a result of ableism, abuse, poverty, or racism—is stress, too.** All stress takes a toll on bodies and minds, and it can show up in lots of ways, some unexpected. Even if the individual is used to the chronic stress they experience or doesn't feel very emotionally affected by it, it can still cause speech or language loss. There's a lot of chronically stressful situations an individual can't change on their own, so remember that reducing stress isn't always an option. But understanding the source of the stress—and having safe spaces to talk about it—can help make things easier, and can help the person to better understand their communication barriers.

- **Know that some people <u>never</u> have access to speech as a reliable form of communication.** The advice in this guide is equally applicable to anyone who needs AAC tools or supports to communicate, whether that's full-time, sometimes, or only occasionally. However, be aware that full-time AAC users are disproportionately exposed to dehumanization, neglect, and abuse from both authority figures and peers, and their experiences with speech and language disability may be very different from people who can sometimes speak. Respect and listen to the individual, and honor their communication and experience.

More Strategies for Effective Communication

- Patient-Provider Communication's repository of free communication boards[4]
- More free "low-tech" AAC resources for adults[5]
- Tactus Therapy's word-finding strategies for aphasia (may be helpful to anyone who struggles with word-finding)[6]
- Tips for communication with people with aphasia (may be more broadly applicable)[7]

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[4] Patient-Provider Communication. (n.d.) Communication tools and materials. https://www.patientprovidercommunication.org/tools-and-resources/communication-tools-and-materials/.

[5] Young, L. A. (n.d.) *Free low-tech AAC for adults* [Blog post]. Eat Speak & Think. https://eatspeakthink.com/free-low-tech-aac-for-adults/

[6] Sutton, M. S. (n.d.) *How to: Word-finding strategies for aphasia* [Blog post]. Tactus Therapy. https://tactustherapy.com/word-finding-strategies-aphasia/#

[7] Forsyth, P. (2016). *Communication tips for successful conversations for families and caregivers of people with aphasia.* Secondary Stroke Prevention Clinic, Lake of the Woods District Hospital. https://tbrhsc.net/wp-content/uploads/2016/07/communication-tips-for-successful-conversations.pdf

- Rees, Forrest, & Rees, 2018: Assessing and managing communication needs in people with serious mental illness (peer-reviewed; paywalled)[8]

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CommunicationFIRST is the only nonprofit organization dedicated to protecting and advancing the civil rights of the more than 5 million children and adults in the United States who, due to disability or other condition, cannot rely on speech alone to be heard and understood. To learn more and support our mission, visit communicationfirst.org.

This resource was created by CommunicationFIRST, a partner of The Link Center, a national resource center funded by the Administration for Community Living (ACL). It works to improve supports available to children and adults with intellectual and developmental disabilities (I/DD), brain injuries, and other cognitive disabilities with co-occurring mental health conditions. The Link Center provides training and technical assistance and advances systems change that will increase access to effective services and supports for people with co-occurring conditions. To learn more, visit https://acl.gov/TheLinkCenter.

[8] Rees, H., Forrest, C., & Rees, G. (2018). Assessing and managing communication needs in people with serious mental illness. Nursing Standard. https://doi.org/10.7748/ns.2018.e11104;