



CommunicationFIRST

Because communication is a human right.

**Comments of CommunicationFIRST
in Advance of the April 13-14, 2022 Meeting of the
Interagency Autism Coordinating Council**

Submitted April 1, 2022

These comments supplement the invited 3-minute Zoom comments that will be delivered by Bob Williams, CommunicationsFIRST's Policy Director, at the IACC meeting on 1:00 pm on April 14, 2022 (Email: bwilliams@communicationfirst.org).

- (1) **ABOUT CommunicationFIRST:** CommunicationFIRST is the only organization focused on the rights and interests of the estimated 5 million people in the United States who must rely on communication tools and supports to be heard and understood. We are led by and for people with speech disabilities, including Board member Jordyn Zimmerman, who will be presenting during the afternoon IACC session on April 14, and Policy Director Bob Williams, who will present brief comments by Zoom at 1:00 pm ET on April 14. CommunicationFIRST is cross-disability in focus, representing people who have had speech disabilities since birth, as well as those who acquire speech loss later in life, for example, due to ALS or Parkinson's. Autistic people are one of the largest segments of our community.
- (2) **IACC STRATEGIC PLAN PRIORITY COMMENTS:** CommunicationFIRST submitted comments on the IACC's Strategic Plan last November. Those comments, which are focused on nonspeaking and minimally speaking autistic people and their communication and other support needs, can be accessed here: <https://bit.ly/3iRwefT>.
- (3) **RECOMMENDATIONS:** We encourage the IACC to take the lead on the following efforts:
 - (a) **Representation in IACC Work:** Increase the representation of nonspeaking autistic people and other users of augmentative and alternative communication (AAC) in the work IACC engages in relating to nonspeaking autistic people and those who must rely on AAC to be understood. We wish that more than 15 minutes of a 2-hour IACC session on the topic of "Perspectives on Addressing Diverse Communication Needs in Autism" involved getting the perspective of an autistic person with communication support needs. We strongly urge that the IACC hold additional listening sessions and other means of soliciting the views and insights of nonspeaking autistic persons. Time limitations are one of the greatest barriers that all people who use AAC face when expressing themselves. The IACC should seize on this opportunity to demonstrate how government and others can alleviate these hurdles.

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- (b) **Representation in Research:** Include people who cannot rely on speech to be understood in research about them. Such research should be guided and advised by people who use AAC. Research funding priorities should be dictated by those who most stand to benefit from such research. This is one of the most neglected populations in terms of federal funding and very little government-funded research on our population has actually improved our lives. We call on the IACC to urge government funders to include AAC users as reviewers on all relevant grant applications. This will help ensure research funding is prioritized for studies that have the potential to improve our lives.
- (c) **Improve Population and Demographic Data:** There is very little data on the numbers, characteristics, and unmet needs of people who cannot rely on speech to be heard and understood. CommunicationFIRST is helping to lay the groundwork to remedy this (see <https://communicationfirst.org/aac-counts/>), but the IACC can and should play a leading role in this effort, especially as it pertains to the autistic portion of this community.
- (d) **Improve AAC-Related Research Generally:** We know that AAC is in its infancy. Compared to the communication tools and supports available for those with the other two main types of communication disabilities – vision (Braille) and hearing (American Sign Language) – AAC is slow, clunky, expensive, unreliable, difficult to use, and generally inadequate to ensure communication equity. We know it is difficult to do this kind of research given how heterogeneous our characteristics and support needs are, but this is not a justification for opting not to conduct it. Such research is necessary and must be done. Great strides are being made on brain-computer interface technologies, but it will likely be decades before those tools are deployable to the average person who needs them. In the meantime, we need to improve AAC tools and supports. Equally importantly, we need to improve our understanding of why so many existing AAC tools and supports do not adequately meet the needs of people with speech-related disabilities. Too many people with significant speech-related disabilities are given up on when they don't intentionally use basic picture cards to request items. We need research that sheds light on the undoubtedly many factors that help explain why this appears to happen and what we can do to better understand and support these individuals. Too many educators, family members, and professionals assume that a lack of reactive or intentional movement means they are “noncommunicative” or “nonverbal” and cannot use more robust, language-based AAC, when nothing could be further from the truth.



- (e) **Improve AAC Deployment:** We believe that the vast majority of the nonspeaking one-third of autistics in this country—hundreds of thousands of people—have not been given access either through the education system or the adult services system to the tools they need to communicate agency, autonomy, self-determination, or to participate in appropriate educational and employment opportunities. As a result, we believe this is the largest underserved population of autistics in the United States. Autistic people of color, or those whose primary language is not English, who need but have been denied access to robust AAC face even greater inequities and marginalization. AAC should be introduced to everyone who has any kind of a speech delay as soon as the delay is evident, as early as 18 months. Researchers at Pennsylvania State University are successfully introducing AAC to infants as young as 6 months, but most people aren't given access to robust AAC until they enter school or even later (if ever). Late and inadequate introduction of AAC causes a vicious cycle where students are given insufficient tools and supports to communicate, and then are blamed for not having the capacity to learn to communicate using language. They should also be provided with age-appropriate literacy instruction no later than their nondisabled peers. Developing strong reading and writing skills is essential to everything else these kids will aspire to and achieve in life. The goal should be that anyone who can benefit from AAC is proficient at using robust, language-based AAC by the time they enter kindergarten, if not sooner.
- (f) **Improve Research About Nonspeaking Autistic People:** So much of the existing published research on nonspeaking autistic people continues to baselessly conflate lack of speech with intellectual disability. We know that speech is a motor function and language is a cognitive function, and that they are processed and generated in different parts of the brain. But researchers continue to assume, without anatomical basis, that someone who cannot speak or move their body reliably also has a language or intellectual disability. All current standardized measures of cognition and “intellectual ability” assume the student or research subject can either speak or move their bodies in intentional ways. There currently is no standardized way to measure intelligence that does not involve planned and initiated movements. We know from countless studies published over the past 20 years that sensory and motor-related disabilities are a core feature of nonspeaking autism. Previously published research about nonspeaking autistic people that discounts the sensori-motor disability elements and assumes intellectual disability without valid proof should be viewed with caution at the bare minimum. Additional research on this front is desperately needed. History is replete with examples of how the research got it terribly wrong about autistic people. We need to constantly seek greater understanding of the abilities and need for communication support of all nonspeaking autistic persons.



- (g) **Stop Funding Research that Utilizes Existing Standardized IQ-Type Measures on This Population:** Nonspeaking autistic people and others who need AAC but are not yet proficient with robust, language-based AAC should never be assessed using standardized IQ-type measures, which are discriminatory and not evidence-based for people with motoric disabilities who cannot speak. Inaccurate low IQ scores are routinely used to deny such people access to robust AAC, creating a vicious cycle and leading to segregation and denial of educational opportunities. There are dozens if not hundreds of nonspeaking autistic people, including our Board member Jordyn Zimmerman, who is presenting to you on April 14, whose IQs were assessed in the “severely” intellectually disabled range before they acquired access to AAC. The existence of a single nonspeaking autistic person who has proved the IQ construct wrong should serve as a caution to researchers. Moreover, federal agencies that fund such research must reconsider the discriminatory consequences of such research and whether it should continued to be underwritten with federal funds.
- (h) **Be Careful About Terminology:** Finally, language matters. The terms “nonverbal,” “minimally verbal,” and “noncommunicative” to describe people who cannot depend on their natural speech to be heard and understood are inaccurate and harmful. They are inaccurate because they imply that the person has a language disability, which is impossible to know if the person has not been provided with adequate language-based communication tools and supports. They are harmful because that embedded assumption results in a denial of access to robust, language-based AAC for those who need it. Terms like “severe” and “profound” are vague and dehumanizing. Like the terms “special needs” and “complex communication needs,” they are also othering. Every human has a need to be heard and understood, and those needs fluctuate from time to time. Some people may require substantial supports to be understood, but the need to communicate is not “special” or “complex.”

(4) CONCLUSION: We ask the IACC to provide bold leadership in supporting this neglected portion of the autism population by working to ensure that every single person is given the tools and support they need to communicate effectively. Introducing robust, language-based AAC is essential for anyone who cannot rely on speech to be heard and understood. When a person is provided access to (including the necessary support to use and learn to use) robust AAC tools, the most significant barriers to education, employment, social engagement, self-determination, decision-making, and community living are alleviated.

Thank you for your consideration.