



Research Priorities: AAC and People Who Need and Use AAC

In July 2023, the National Institute on Deafness and Other Communication Disorders (NIDCD) sent out a [Request for Information](#) (RFI) about how NIDCD should spend millions of dollars of government funding on research related to augmentative and alternative communication (AAC) and people with speech-related disabilities. **Comments are due by September 15, 2023. We encourage as many AAC users as possible to share your research priorities with NIDCD.**

CommunicationFIRST has developed **two resources** to help you: (1) this document, which lists sample research ideas to help get you started; and (2) [this document](#), which describes what research is and why it is important.

Your ideas are critical to making AAC research better for everyone. Whenever possible, try to use your own words in your comments instead of copying language from this document. Our advocacy will have the biggest impact when NIDCD hears directly from AAC users, in your own words, about what's most important to you personally.

Some of the questions ask about difficult, stressful, or sensitive things. We encourage you to pay attention to how you are feeling, and respect your limits.

We've organized this resource by the four topics that NIDCD has asked about. (Note that these are plain language versions of the topics, not the language NIDCD used.)

1. [Greatest Unmet Needs of AAC Users](#) (How has AAC failed us? What changes do we need to see in society?)
2. [Roadblocks to Effective Communication for All](#) (What makes it hard to access effective AAC?)
3. [Priorities in Our Lives](#) (What are some of your biggest worries as an AAC user?)
4. [Research Process Issues](#) (What would make it easier for you to work with researchers? What does good research look like to you? What does bad research look like to you?)

How to Submit Your Comments

You may want to start by writing your ideas in a separate document. This can help make sure you don't accidentally lose your work, and gives you the freedom to edit. You can tell NIDCD whatever is important to you, as much or as little as you think they should know.



- **Email:** Comments can be emailed to: NIDCDMinVerbRFI@nidcd.nih.gov.
- **Webform:** Shorter comments (less than 2,000 characters per topic) can be submitted on this webform: <https://www.nidcd.nih.gov/nidcd-minimally-verbal-rfi>.

We'd like to keep track of the ideas AAC users submit to NIDCD so we can follow up as necessary, so please email a copy of your comments to: info@communicationfirst.org. You may not receive a response from either NIDCD or us, but you can be sure your comments will be read!

Context

Although the field of AAC has existed for more than 40 years, it has yet to make much of a change in our lives. Too much of the research funded by the federal government relating to AAC and people who cannot rely on speech to be heard and understood has not led to meaningful improvements in our lives:

- Most of us still lack access to robust, language-based AAC.
- Most of us are segregated from the rest of society.
- Most of us are denied meaningful educational and employment opportunities.
- Most of us live in poverty.
- Most of us have almost no agency, autonomy, or decision-making power over our own lives.
- Most of us will be abused at least once in our lifetimes.

We still do not have very effective tools that allow most of us to be understood. We also continue to be routinely excluded and isolated from society and denied educational, social, living, and employment opportunities that our peers without expressive communication disabilities enjoy. The reasons for this are widespread discrimination, ableism, and bias and misperceptions about us.

What research will have the greatest positive impact on our well-being? What research will make the biggest difference in our lives? We need to help the government understand these questions.

Language matters, whether it's in conversations or publications. Terms such as "nonverbal" and "minimally verbal" can do real harm, directly or indirectly, to people who need AAC.

CommunicationFIRST's [Words We Use resource](#) goes into detail about this and other terms, both helpful and harmful, and presents some alternatives.



Sample Research Priority Ideas

TOPIC 1: Greatest Unmet Needs of AAC Users

- **Accessing AAC**

- Why do so many people mistakenly believe that **if we can't speak we also cannot understand and use language**? What's the best way to do away with that myth?
- How do we do a better job of **teaching all people** who cannot rely on speech to be heard and understood to read and express language? How are the needs of **adults with acquired AAC needs** different from those who need AAC for their whole life?
- How can we ensure that children are already skilled at using some kind of **language-based AAC before we enter kindergarten**?
- What do we **feel and experience** during the early stages of being introduced and supported to use a language-based AAC system?
- How do we **shift the burden of advocating for and enforcing communication accommodations** to those who are best equipped to provide those accommodations?
- Why are we "blamed" for not using AAC systems, instead of the professionals, technology, and supports around us? Calling this "**abandonment**" places the burden on us, instead of on the structural issues that made us unable to use the system.
- How can we ensure we can **access all the various types of AAC we may need** in our lives, rather than having the focus usually be on a single high-tech system?
- How do we ensure that people **living in certain settings**, like institutions, group homes, or jails, are not denied access to AAC, or lose access they already had?

- **Relationships and Conversations**

- How can we change society so that other people give us the **time, space, respect, and dignity** to express ourselves?
- What do we need to do to ensure we are able to have **more meaningful and equitable relationships** and friendships?
- How do we develop AAC that will allow me to **communicate as quickly** as my friends who do not have speech disabilities?



- How can AAC research focus more on **conversational agency**, including topic relevance after a delay in communicating, who is addressed during a conversation, talking over an AAC user, talking for an AAC user, and asking permission of us?
- **Human AAC Supports**
 - What are the **essential qualities** of a communication aide or support person?
 - What are the **roles of trust and safety** in establishing a successful partnership?
 - What **ethical principles** should be required of a communication assistant?
- **Accessing Society and Opportunities**
 - How do we change society so that we aren't as **segregated and isolated** in education and in life?
 - How do we do a better job of including us to be **full, participating members** of our communities?
 - How can we do a better job of giving us the skills we need to **be employed**, and giving employers the skills they need to **be good employers**?
 - What needs to happen so that I can **report emergencies and crimes** as easily as my non-disabled friends can?
- **Access to Identity-Related Features**
 - Is there a mechanism to ensure that technology manufacturers **prioritize identity-related features**, including creating more voices so we can sound different from each other, adding emphasis and inflection options to so we can communicate emotions, allowing us to communicate using different accents and genders that match our individual and cultural identities, the ability to code-switch, code-mix, and use multiple languages?

TOPIC 2: Roadblocks to Effective Communication for All

- **Fundamental / Macro Questions**
 - How do we **improve national data** about people who need AAC (see the [AAC Counts Project](#))? How many of us exist, and how many of us who need AAC still don't have access to it?



- Why hasn't 40 years of AAC research **improved our lives very much**? Why don't existing AAC systems work very well to help us communicate and be understood? We need studies on the **long-term outcomes** of specific AAC "interventions." What do we as AAC users consider to be good outcomes versus bad outcomes?
 - **Why is it so hard** for so many of us to get access to robust, language-based AAC?
 - How can we ensure future research focuses on **our quality of life**?
 - What does it mean for AAC to be "**effective**?" What needs to be in place to ensure we can **communicate effectively**? Who decides?
 - How do we make sure that **assumptions about our ability to read (or learn to read)** don't prevent us from being given access to language-based AAC?
 - Do all AAC users **learn language differently** from people who don't need AAC?
 - How can we increase the number and stability of **skilled communication support people** who are available to support us in school, jobs, and life?
 - How do we improve our understanding of how factors like sex, race, ethnicity, and class impact **differences in communication access**? Why do some **multiply marginalized groups** experience greater barriers to accessing AAC?
 - What are best practices for **assessing or determining our decision-making "capacity" in legal contexts**, and how does that vary depending on whether we have or lack access to robust, language-based AAC?
- **Obstacles to Individual Access to AAC**
 - How do we stop the common practice of **having IQ tests used against us**?
 - So much existing research about us continues to assume that if we cannot speak we cannot understand and use language and therefore have an intellectual disability. This is largely because existing measures of "intellectual ability" assume the person can either speak or move their body in intentional ways. Although some of us do have ID, that does not mean that we cannot understand language or use language-based AAC.
 - What are the most effective ways to **teach us** how to use a new AAC system?
 - What factors explain why some of us **need more support than others** in learning to use AAC fluently and with minimal support?



- What are the best strategies for dealing with **support people who believe** we are not capable?
- How do **different circumstances and contexts** affect communication and the types of AAC tools and levels of support that we might need?

TOPIC 3: Priorities In Our Lives

- **Access: Early and Always**

- How do we **spot the need for AAC as early as possible** and ensure babies who will need AAC are introduced to it as soon as possible?
- How do we ensure that we have access to all the AAC tools and supports we need **at all ages of our life, at all times of the day, and in all places?**
- How do we make sure **other types of technologies** are developed with AAC users' needs in mind so that they are accessible to us?
- How can we make sure that AAC software and hardware that we have come to rely on to exercise the basic human right of communication isn't "**phased out**" by manufacturers?

- **Bias, Discrimination, Equity, Power**

- How can society better understand **speechism** and **bias** against us? How can research on negative outcomes with AAC "intervention" begin to take into account the impacts of denying literacy and appropriate education, segregating us, restraining and secluding us, isolation and loneliness, and dehumanization?
- How can the **power imbalances** between AAC users and people who do not need AAC best be measured? Researchers (and others who interact with us) must be able to identify power imbalances and be aware of their effects on our interactions.
- As we better understand **speech privilege**, we should begin to identify ways to reduce power imbalances between people with and without speech disabilities. What might that look like during a conversation? How can **interactions** between AAC users and non-AAC users be made fairer and more equitable?
- We need to investigate the reasons for and impacts of bias against us in **healthcare settings**, such as taking away our AAC devices and listening to support workers or family members instead of us.



- How do healthcare providers' **assumptions about our quality of life** impact the quality and type of health care we are provided?

- **Mental Health, Trauma, Abuse**

- Is it true that anyone who has ever experienced any significant period of time unable to communicate their thoughts has experienced **trauma**? Even after accessing AAC, we are likely to struggle with the effects of this trauma for the rest of their lives. Being denied access to robust AAC when it's needed may constitute an "**adverse childhood experience.**" We need to understand how this developmental trauma affects long-term outcomes.
- Should all of us be approached with **trauma-informed practices and principles**?
- Do we understand **how trauma affects our ability to learn and use** robust, language-based AAC?
- How can we develop appropriate services and strategies to **prevent daily retraumatization** from things like communication barriers and ableism?
- We need to know more about the **circumstances and rates of abuse** we experience, and how that may vary depending on whether we have access to robust, language-based AAC.
- How does having a speech-related disability affect mental health and **outcomes related to mental illness**, including self harm and suicide?
- How does lacking language-based AAC and **the stigma** surrounding AAC and speech disability affect our social and psychological lives?
- How do **loneliness and isolation** affect us? What can help alleviate our isolation and loneliness?

- **Institutionalization and Guardianships**

- How can we ensure that **we aren't institutionalized** when loved ones pass away?
- What is the role of having access to effective, language-based AAC in determining whether we **can utilize supported decisionmaking** instead of having our rights taken away in a guardianship or conservatorship?
- How can we reduce the practice of **automatically taking our rights away** when we turn 18?



- What are the **impacts of institutionalization and guardianships / conservatorships** in our lives and to our mental health?
- What **unique challenges, biases, and rights violations** are we more likely to face in institutions?

TOPIC 4: Research Process Questions

- **Improving Representation in Research, Design, and Priorities**

- What are the best ways to **get input from us** about research design and priorities?
- What **could NIDCD do better** to ensure it receives **meaningful input** from a variety of people who use AAC? Ideas that can be explored are:
 - Create an **advisory panel of AAC users** to advise NIDCD on RFIs (Requests for Information), RFPs (Requests for Proposals), grant proposals, and grant awards that relate to AAC or people who need AAC. Research that gets funding and support should be research that matters to us.
 - Work with an advisory panel of AAC users to **develop a rubric** to measure the potential of each grant proposal to actually improve our lives.
 - Require that each NIDCD AAC-related grant-funded program be governed, evaluated, or overseen at least in part by a panel of AAC users, or otherwise require each to meaningfully utilize **community-based participatory research (CBPR)** best practices.
 - **Require researchers to consult with AAC users at all stages** of research, from study design, to grant proposals, to analyzing results.
 - NIDCD should focus generally on **improving the usefulness and relevance** of research to us. Funding should be dedicated to research that will actually lead to an improvement in our lives.
- What steps will ensure there are **more researchers who are AAC users**?
- How can lessons from **participatory action research** be incorporated into NIDCD funding for AAC-related grants?
- How can **research methods and ethical guidelines be improved** to ensure researchers communicate directly with us in studies (as opposed to using proxies)? Assisted response, first used in the 1994-1995 NHIS-D, is one alternative to proxy response. How do we develop unique ethical guidelines on **consent and assent** for people who need and use AAC?



- What are ways researchers can **privilege and understand responses** from those of us who have been denied access to robust, language-based AAC?
- How do we debunk the narrative that we are less qualified than nondisabled parents to **represent the interests of people with speech-related disabilities**?
- **Cross-Disability Focus**
 - How do we ensure we move away from disability-specific research silos toward a **cross-disability focus** on people with speech disabilities and the needs we have?
- **Preventing Dangerous Ideas**
 - How can we transition AAC research funding from the medical model to a **social model of disability**?
 - How can we **guard against eugenicist ideas in research about us**, like classifying us based on the “severity” of our disability and support needs? Focusing on individual conditions and differences at the expense of cross-disability knowledge isn’t just a waste of resources, it’s potentially dangerous. This overspecialization is also a hallmark of eugenics, especially when combined with other eugenicist strategies like “disease registries,” which have potential research benefits but may carry far greater social harms.



APPENDIX

NIDCD's AAC-Related Research Funding Priorities in 1994

- (a) Study the impact of AAC technologies on the development of communication, language, natural speech, and discourse skills of persons with severe communication disorders;
- (b) Study the influence of user variables (e.g., knowledge, skill, and learning style) on AAC system use;
- (c) Investigate the impact of AAC system features on communicative competence and interactional skills of users;
- (d) Develop tools and strategies to validly and reliably measure communicative, operational, linguistic, strategic, and social competence of children and adults who use AAC systems;
- (e) Investigate the effectiveness of AAC interventions by studying users of a variety of ages, etiologies, and social contexts and to determine those factors that are related to success and failure of AAC use; and
- (f) Encourage the academic development of researchers with a focus in AAC by establishing pre-doctoral and post-doctoral research and training opportunities.