



CommunicationFIRST

Because communication is a human right.

Comments of CommunicationFIRST
to the
**National Institute on Disability, Independent Living, and
Rehabilitation Research (NIDILRR)**
on its
2024-2029 Long-Range Plan

Submitted via NIDILRRFuture@neweditions.net

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CommunicationFIRST is pleased to submit these comments for consideration by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) as it develops its [2024-2029 Long-Range Plan](#). We strongly support NIDILRR's mission to improve the quality of life for people with disabilities by (1) expanding the opportunities for disabled people to perform activities of our choosing in community settings, and (2) expanding society's capacity to fully include and accommodate us.

I. Introduction

CommunicationFIRST is the only disability-led organization dedicated to protecting the rights and advancing the interests of the estimated 5 million people in the United States who must rely on communication tools and supports to be heard and understood due to speech-related disabilities and conditions. We are led by and for people with speech disabilities, and are cross-disability in focus, representing people who have had speech disabilities since birth, such as those with Down syndrome, rare genetic syndromes, cerebral palsy, and autism, as well as those who acquire speech loss later in life, for example, due to ALS or Parkinson's. More information about CommunicationFIRST can be found at <https://communicationfirst.org/>.

NIDILRR is one of the more significant funders of research and development activities that impact people who cannot rely on speech to be heard and understood, including related to augmentative and alternative communication (AAC) tools and supports that are paramount for ensuring our ability and civil rights to communicate effectively, become educated and employed, and to be a part of our communities. In these comments, we encourage NIDILRR to do more to increase equity for people with significant

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speech-related disabilities, especially people who must rely on AAC tools and supports to be heard and understood. **People who cannot use speech to be understood are among the most marginalized, segregated, and least equitably supported groups of people in the country.** We recommend NIDILRR, therefore, take the following types of actions to begin to both avoid and redress the consequences of these and related inequities.

II. Formally, Meaningfully, and Respectfully Engage People Who Need AAC in NIDILRR Grant-Making and NIDILRR-Funded Research and Development Activities

Although the field of AAC research has existed for over four decades, it remains in its infancy in terms of how well it has succeeded in improving the quality of life, educational, employment, and self-determination opportunities for people with significant speech disabilities. Compared to the communication tools and supports now available for children and adults with sight and/or hearing disabilities, many existing forms of low and high-tech AAC are slow, expensive, unreliable, difficult to learn to use, and often do not enable people who need AAC to communicate effectively with language. Some AAC fails to provide any way for someone using it to spell words or phrases. The rationale given for this is that some individuals communicate on a “presymbolic level,” and so have no need to access letters, and no ability to use or even understand language. This logic is reductive, circular, and dangerous. Many people who require AAC have been treated as “functioning on a presymbolic level” for decades of their lives, only to later show that they could read and write. Yet, this travesty of justice continues. As Janice Light, Ph.D., the Principal Investigator of NIDILRR’s [RERC on AAC](#), recently noted:

Ultimately, our goal is independent, generative communication and we know how incredibly important literacy is to meeting that goal. Literacy skills are absolutely essential to all of us for participation in society and more important for individuals who have limited speech because it is only through literacy that they have access to independent generative communication without relying on others to provide them with access to picture symbols to allow them to communicate. It is disturbing to see that **more than 90 percent of individuals who have complex communication needs enter adulthood without functional literacy skills.** There are a wide range of reasons for this but one of them is that current AAC technologies do not support the transition from picture symbols to literacy.¹

¹ https://iacc.hhs.gov/meetings/iacc-meetings/2022/full-committee-meeting/april13-14/transcript_day2.pdf (pp. 140-41)



While we know of no research on the matter, we believe it is highly probable that persons who acquire the need for AAC as working age or older adults face equally daunting odds in gaining or regaining literacy and the related skills necessary to access, learn to use, and effectively communicate with robust, language-based AAC. There is a gap in general understanding among nondisabled people about how and when to provide and ensure meaningful access to AAC for those who need it. As a result, little progress is being made to improve the lives of the majority of such individuals. Studies indicate that Black, brown, and non-English-speaking people are more likely to acquire the need for AAC through life, and to experience heightened barriers and discrimination because of this. Such inequities are substantial, and given its history and mission, NIDILRR has the tools, orientation, and duty to take the lead in identifying and eliminating them. NIDILRR should enlist the support of the Centers for Medicare and Medicaid Services (CMS), the U.S. Department of Education's Office of Special Education and Rehabilitative Services (OSERS), the National Institute on Deafness and Communication Disorders (NIDCD), the U.S. Department of Veterans Affairs (VA), and other agencies in developing, funding, and implementing such an effort.

To this end, NIDILRR must ensure that individuals who currently use AAC play a substantive role in all stages and aspects of research that is proposed or carried out about us. Research funding priorities should be set in continuing dialogue with those who most stand to benefit from such research. **We call on NIDILRR to take the lead among government funders** in engaging and increasing the meaningful participation of people with significant speech-related disabilities in grant-making activities that impact them, by:

1. **Creating an advisory panel of AAC users to help develop a rubric by which NIDILRR can measure the potential of each grant proposal to improve the lives of people who need AAC;**
2. **Including AAC users as reviewers on all NIDILRR RFIs, RFPs, grant proposals, and grant awards that relate to AAC or people who need AAC; and**
3. **Requiring that each NIDILRR grant be governed, evaluated, or overseen at least in part by a panel of AAC users, or by otherwise requiring each grantee to meaningfully utilize best practices in community-based participatory action research.**

We also urge NIDILRR to lead the aforementioned cross-agency effort in equal partnership with persons who use AAC from the diverse, multiracial, multicultural,



multigenerational, multilingual, cross-disability backgrounds outlined above that are designed to:

1. **Identify, redress, and take actions to avoid the increased risk that research indicates Black, brown, and non-English-speaking people are more likely to acquire the need for AAC over the lifespan, be denied it, and experience greater bias and discrimination as a result;**
2. **Identify, promote, and scale promising and evidence-informed practices that dramatically and measurably increase the literacy and AAC access rates of all who require AAC beginning at 6 months old and throughout life; and**
3. **Concomitantly cut illiteracy among such children, working age persons, and older adults in half by July 26, 2030, the 40th anniversary of the ADA.**

Finally, language matters. **The terms “nonverbal,” “minimally verbal,” and “noncommunicative” to describe people who cannot depend on their own 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. Similar terms such as “special needs” and “complex communication needs,” are easily misinterpreted and othering.** Every person has the basic need and the fundamental right 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.” As NIDILRR takes steps to substantially involve our members in setting priorities and other facets of its research agenda to improve the lives of people who need and use AAC, we encourage the agency to choose the nomenclature it uses carefully and in continuing consultation with those most affected by its choices.

III. Research and Development Funding Priorities

We encourage NIDILRR to prioritize the following issues in future grant-making activities that impact people with significant speech-related disabilities:



- 1. Improve Demographic and Population 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. Who are we? How many are we? What are our unmet needs? How educated are we? How healthy are we? How impoverished are we? What are our rates of unemployment? What is the extent of our marginalization, isolation, and lack of access to robust, language-based AAC? CommunicationFIRST is helping to lay the groundwork to remedy these data inequities (see <https://communicationfirst.org/aac-counts/>). NIDILRR and its Interagency Committee on Disability Research can and should play a leading role in this effort to improve the collection, analysis, and availability of demographic and characteristic data on people who require AAC.
- 2. Eliminate Intersectional Barriers to AAC Access:** Black and brown people and English learners face the lowest expectations and the greatest prejudice and disparities in accessing effective communication tools and supports. Too many people with significant speech-related disabilities are given up on when they do not intentionally use basic picture cards to request items. Clinicians and educators have historically prioritized speech over all other forms of expressive communication (e.g., by promoting oralism, or erecting stringent prerequisites for accessing AAC). Very few medical providers, educators, related service providers, and direct support professionals have the skills necessary to train and support the use of AAC. But even those fortunate enough to receive some access, training, and ongoing support to use language-based AAC frequently lack equal access to education, employment, and community opportunities because such tools are slow, expensive, difficult to learn, difficult to access, and difficult to utilize. More research is needed to identify and ameliorate the disparate factors that cause people from racial, linguistic, and other minority communities to be both more likely to have developmental and acquired disabilities that may make their use of AAC necessary and to face greater bias and difficulty in accessing it.
- 3. Improve AAC-Related Research Generally:** NIDILRR should fund research and related activities that can improve our understanding of why so many existing AAC tools and supports are failing to 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 use basic picture cards to request



items. Additional research is required to shed light on the undoubtedly multiple 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. As researchers at the RERC on AAC point out, it is vital that literacy learning, mastery, and retention strategies be incorporated in the design and use of all AAC technology, strategies, and supports. Universal design principles and practices that NIDILRR has played such a foundational role in developing, socializing, and bringing to bear on a host of complex challenges offers a powerful framework for achieving this aim.

4. **Improve AAC Deployment:** We believe that the vast majority of people who require AAC continue to be denied it by the education system or the adult services system. Consequently, they are denied the right and opportunities to effectively communicate, to make decisions about their own lives, and to belong to their communities. They are denied any semblance of equal educational, employment, and other opportunities. People of color, and 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. These same principles must apply to individuals who acquire the need as working age or older persons.
5. **Stop Funding Research that Utilizes Discriminatory Standardized IQ-Type Measures:** So much of the existing published research on those of us who do not



use speech to be heard and understood continues to baselessly conflate lack of speech with intellectual disability. This is largely due to the fact that all current standardized measures of cognition and “intellectual ability” assume the student or research subject can either speak or move their body in intentional ways. There currently is no standardized way to measure intelligence that does not involve planned and initiated movements. Inaccurate low IQ scores are routinely used to deny us access to robust AAC, creating a vicious cycle and leading to segregation and denial of educational opportunities. Using biased assessments violates Section 504, the ADA, and IDEA. Federal, state, and local government as well as other covered entities should not continue to use, rely on, or sanction the use of such tools and methods. History is replete with examples of how the research got it terribly wrong about us. There are many people, including CommunicationFIRST’s Board Chair [Jordyn Zimmerman, M.Ed.](#), whose IQ was assessed in the “severely” intellectually disabled range before they acquired access to AAC. The existence of a single person who has proved the IQ construct wrong should serve as a caution to researchers. We need to seek greater understanding of the abilities and need for communication support of all people who need but continue to lack meaningful access to robust AAC. And, in the meantime, people who need it but are not yet proficient with robust, language-based AAC should never be assessed using standardized IQ-type measures, which are discriminatory, harmful, and not evidence-based for people with motoric disabilities who cannot speak. **NIDILRR and other federal agencies that fund research about us must reconsider the discriminatory consequences of such research and whether it should continued to be underwritten with federal funds.** Similarly, NIDILRR and its federal research partners should fund research and demonstration actions to develop, scale, and socialize assessments that can be shown to produce results that are fair, accurate, and equitable with respect to this cohort.

IV. NIDILRR Staffing Initiatives

Even compared to the broader population of people with disabilities, the unemployment rate of people who use AAC is abysmal. This is due to persistent and unwarranted assumptions that we are “unemployable” and have no skills or desire to pursue careers. Nothing could be further than the truth. To challenge such ableism and its consequences, as it develops its 2024-2029 Long Range Plan, we encourage NIDILRR to:



- (1) Survey the NIDILRR workforce to determine what percentage of its employees currently use AAC, together with their characteristics, careers, and aspirations;
- (2) Seek the advice and insights of these NIDILRR employees and others using AAC pursuing careers in the sciences and other fields on the qualities of model employers;
- (3) Study, elevate, and apply lessons that can be learned from the careers of Dr. Stephen Hawking, PhD, and other researchers who have relied on AAC in their work; and
- (4) Work with the U.S. Departments of Education and Labor to support strategies to increase learning and career opportunities in the sciences for persons who require AAC and others with disabilities.

V. Conclusion

We ask NIDILRR to provide bold leadership in supporting this neglected portion of the U.S. 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.

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We appreciate this opportunity to comment. If you have any questions, please do not hesitate to reach out to Bob Williams, Policy Director, at info@communicationfirst.org.