



CommunicationFIRST

Because communication is a human right.

Comments of CommunicationFIRST
to the
**National Institute on Disability, Independent Living, and
Rehabilitation Research (NIDILRR)**
on its
Draft 2024-2028 Long-Range Plan

Submitted via NIDILRRFuture@neweditions.net

October 13, 2023

CommunicationFIRST is pleased to submit these comments for consideration by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) on its [Draft 2024-2028 Long-Range Plan](#).¹ If you have any questions regarding these comments and recommendations or any aspect of our work, please do not hesitate to contact CommunicationFIRST Policy Director Bob Williams or Executive Director Tauna Szymanski at info@communicationfirst.org. More information about CommunicationFIRST can be found at <https://communicationfirst.org>.

I. Introduction

CommunicationFIRST is our nation's only organization led by and for and dedicated to protecting and advancing the rights of the estimated five million people of all ages in the United States who need communication tools and supports to be heard and understood due to speech-related disabilities and conditions. We thank NIDILRR for this opportunity to comment on its Draft 2024-2028 Long-Range Plan and the thought and work that so many people have invested in its development.

CommunicationFIRST also particularly appreciates the decades of investment NIDILRR has made in the Rehabilitation Engineering Research Center on Augmentative and Alternative Communication ([RERC on AAC](#))² and, more recently, its support of Disability and Rehabilitation Research Projects on Technology for Expressive

¹ <https://neweditions.net/media/96>

² <https://rerc-aac.psu.edu/home-page/>



Communication ([Project Open](#)).³ The work of these endeavors and many other R&D investments NIDILRR has made since the 1970s continues to enhance the lives, civil rights, equal opportunities, and futures of so many of our members⁴ and other people with disabilities. It is on the basis of ensuring this continued progress and success that we offer the following comments and recommendations on NIDILRR’s Draft Long Range Plan for 2024-2028.

We believe it is crucial that we ground our comments and recommendations in the lives of the uncounted millions of us who require augmentative and alternative communication (AAC). We will begin by providing a description of our organization, our members, and the widespread bias and discrimination we face.

II. About CommunicationFIRST

CommunicationFIRST is a cross-disability, cross-generational, multi-racial, and multicultural disability-led civil rights organization. We do our work as a civil rights and disability justice organization not because it is a silver bullet. We know more must be done. But we also know that until progress is made on the civil rights front, people with little to no understandable speech who need AAC will continue to be marginalized.

III. This Is Us

Led by and for AAC users, CommunicationFIRST seeks to represent all children, young people, working-age persons, and older adults who have little to no understandable speech and must use one or more modes of AAC to express ourselves and be heard and understood. Our diverse members include those who have had disabilities since birth – such as Down syndrome, rare genetic syndromes, cerebral palsy, and autism – as well as those who acquire speech loss at other points in life, including due to ALS, Parkinson’s disease, stroke, traumatic brain injury, and other conditions or injuries.

Similarly, we focus our work on issues where disability, race, ethnicity, and gender, as well as class, culture, and language intersect. We do so because people who need AAC

³ <https://project-openaac.com/>

⁴ We use the term “members” to refer to those whom we seek to represent: All people in our country who require augmentative and alternative communication to express ourselves, be heard, and live our lives.



frequently endure multiple forms of discrimination and oppression throughout life that must be recognized and eradicated.

Our members have disabilities that make it impossible to produce or use spoken words or sign language that is understandable to others. Instead, we must rely on what is referred to as AAC. Broadly speaking, AAC is any tool, method, or support used by a person with a speech disability who cannot rely on speech alone to be heard and understood by others. In addition to having disabilities that limit or make it impossible to physically produce any understandable speech, most of us who need AAC have other significant disabilities. These can include a range of often misdiagnosed behavioral, cognitive, expressive, health-related, independent living, mental health, motoric, receptive, sensory, and traumatic disabilities and conditions. People may need AAC all the time, most of the time, or episodically. AAC includes gesturing; pointing to or looking at letters, words, and images; relying on a personal assistant to repeat one's speech; using commercially available assistive digital devices and apps; brain computer interface technology; and a growing number of emerging technologies.

IV. A Pattern of Pervasive Discrimination and Social Exclusion

Despite the proliferation of digital, mobile, and other technologies in AAC, however, the National Academies of Sciences, Engineering, and Medicine have found that, "Individuals who communicate with AAC experience significant barriers to obtaining and learning to use AAC technology."⁵ Many factors contribute to this. By far the oldest and most virulent and persistent of these are the unwarranted assumptions, stereotypes, and discrimination we still experience based on both individual actions as well as the outdated and hard-wired policies and practices of federal, state, and governmental entities. **In 2023, it is still the norm for countless numbers of our members to be ostracized and perceived and treated as less than: As having less intellect, less to say, and no need or right to do so – all, ironically, because others cannot understand them.**

⁵ National Academies of Sciences, Engineering, and Medicine, Committee on the Use of Selected Assistive Products and Technologies in Eliminating or Reducing the Effects of Impairments; Flaubert, J. L., Spicer, C. M., Jette, A. M., eds., "Chapter 6: Augmentative and Alternative Communication and Voice Products and Technologies," in *The Promise of Assistive Technology to Enhance Activity and Work Participation*, (National Academies Press, 2017), <https://www.ncbi.nlm.nih.gov/books/NBK453284/>.



Consequently, our members are disproportionately denied the tools and support to effectively communicate; wrongfully assessed and stigmatized for life;⁶ deprived of an inclusive, equally effective education; segregated and institutionalized;⁷ isolated and excluded from everyday life, including the ever-more-important digital world;⁸ subjected to inferior health care;⁹ abused and victimized;¹⁰ and far worse. Moreover, research and lived experience suggest that Black, brown, multilingual, and other multiply marginalized individuals are both more likely to need AAC at some point in life and to experience harsh and compounding forms of societal oppression and discrimination as a result.¹¹

⁶ See, e.g., Marilyn Brookwood, *The Orphans of Davenport: Eugenics, the Great Depression, and the War over Children's Intelligence* (W. W. Norton & Company, 2021); CommunicationFIRST, "CommunicationFIRST to DC Council: Eliminate IQ Requirement to Qualify for Services," (Nov. 15, 2021), <https://bit.ly/3PXajUp>; CommunicationFIRST, "Defining 'Intellectual Disability'" (Comments to the American Psychological Association on its Proposed Redefinition of "Intellectual Disability") (Oct. 1, 2019), <https://bit.ly/3FiakOg>.

⁷ See, e.g., Ne'eman, A., Stein, M., & Grabowski, D. C. (2022). Nursing Home Residents Younger Than Age Sixty-Five Are Unique And Would Benefit From Targeted Policy Making. *Health Affairs*, 41:10, 1449-1459. <https://doi.org/10.1377/hlthaff.2022.00548>.

⁸ See, e.g., Kasnitz, D., & Block, P. (2012). Participation, Time, Effort, and Speech Disability Justice, Ch. 14, in *Politics of Occupation-Centred Practice: Reflections on Occupational Engagement Across Cultures*. DOI:10.1002/9781118702819.CH14.

⁹ See, e.g., Morris, M. A., Dudgeon, B. J., & Yorkston, K. (2013). A qualitative study of adult AAC users' experiences communicating with medical providers. *Disability and rehabilitation. Assistive technology*, 8(6), 472-481. <https://doi.org/10.3109/17483107.2012.746398>.

¹⁰ See, e.g., Bryen, D. N., Carey, A., & Frantz, B. (2003). Ending the silence: Adults who use augmentative communication and their experiences as victims of crimes. *AAC: Augmentative and Alternative Communication*, 19(2), 125-134. <https://doi.org/10.1080/0743461031000080265>.

¹¹ See, e.g., Meryl Alper, *Giving Voice: Mobile Communication, Disability, and Inequality* (MIT Press, 2017); Ellis, C., Jacobs, M., Keene, K. L., & Grubaugh, A. L. (2020), The Impact of COVID-19 on Racial-Ethnic Health Disparities in the US: Now Is the Time To Address the Problem. *The Journal of the National Medical Association*; Kulkarni, S. K., & Parmar, J. (2017). Culturally and linguistically diverse student and family perspectives on AAC devices. *Augmentative and Alternative Communication International*. DOI:10.1080/07434618.2017.1346706; De Leon, M., Solomon-Rice, P., & Soto, G. (2023). Perspectives and experiences of eight Latina mothers of young children with augmentative and alternative communication needs. *Perspectives of ASHA Special Interest Groups*, 1-10. https://doi.org/10.1044/2023_PERSP-23-00074; Black, L. I., Vahratian, A., & Hoffman, H. J. (2015). *Communication disorders and use of intervention services among children aged 3-17 years: United States, 2012* (Data Brief No. 205). National Center for Health Statistics. <https://www.cdc.gov/nchs/products/databriefs/db205.htm>; Pope, L., Light, J., & Franklin, A. (2022). Black children with developmental disabilities receive less augmentative and alternative communication intervention than their white peers: Preliminary evidence of racial disparities from



The federal government's actions and, in many instances, inertia and acceptance of an ableist status quo, are not the only reasons these grave injustices persist. However, these are the ugly truths:

- **Laws like the Civil Rights Act of 1964, Section 504 of the Rehabilitation Act, the Individuals with Disabilities Education Act, and the Americans with Disabilities Act are failing us.** These laws are not implemented nor enforced in a comprehensive manner necessary to safeguard and secure the rights, liberties, and lives of all people who require AAC of all races and circumstances.
- **The federal government refuses to gather national, state, and local data on the numbers, needs, and status of individuals with communication disabilities, including those who need AAC.** Federal statistical and research agencies seem to believe maintaining absolute statistical consistency with respect to what survey questions are asked is more important than counting and being accountable to us.
- **Flaws and biased “research” conducted over the years and paid for with federal funds continue to be used to justify the unspoken indignities, mislabeling, abuse, and violence many of our members endure endlessly.** Pursuing new knowledge to end this cruel cycle is vital. The federal government and NIDILRR specifically also must engage simultaneously in a restorative justice process that reveals both the harm that still is being inflicted based on such “research” and the immediate and long-term actions that will be taken to repair such wrongs and to prevent future ones.

The need to challenge and change such ugly truths guides our comments and recommendations and our work. For it to be the credible and effective anti-ableism organization it aspires to become, NIDILRR must explicitly use its tools, resources, and strategic partnerships to expose the untenable harm these ugly truths cause in the lives of millions of people who require AAC and those with other disabilities.

V. Substantive Comments and Recommendations

CommunicationFIRST offers the following comments and recommendations on select topics, themes, and proposed priorities in the order each is discussed in the draft plan.

a secondary data analysis. *American Journal of Speech-Language Pathology*, 31(5), 2159–2174.
https://doi.org/10.1044/2022_AJSLP-22-00079.



A. Target Populations (page 3)

NIDILRR defines its target population as encompassing those with “developmental, cognitive, sensory, psychiatric, and physical disability.” This has been the longstanding practice throughout the government and largely tracks the six disability classes that the U.S. Census Bureau and federal statistical agencies use to determine what cohorts of people with what specific disabilities count and deserve to be counted, **and which of us should continue to be uncounted, go unheard, and subjected to egregious discrimination that goes unnoticed.**

We strongly urge NIDILRR to explicitly include “communication disability” as a target population in its final plan and to use its prestige and relationships to convince other federal agencies, including statistical agencies, to take similar actions discussed below. As CommunicationFIRST and the Disability Rights and Education Defense Fund (DREDF) document in *AAC Counts: The Urgent Need for Better Data About People with Significant Speech Disabilities*:

People in the United States who cannot rely alone on speech to be heard and understood are not counted in any systematic manner by federal or state governments. Failing to accurately track our characteristics, access to services and supports, and unmet needs makes it impossible for policymakers and advocates to appreciate and address the challenges, barriers, and intersectional discrimination we grapple with each day.¹²

Some data is periodically gathered on people with expressive communication disabilities in the National Health Interview Survey (NHIS) and Survey of Income and Program Participation (SIPP). However, none of this data can be used to produce zip code, community, or even state-level estimates and insights. Such data also fails to identify or provide any information at all about the demographics, integration, participation, segregation, or unmet needs of people in this country who require AAC. NIDILRR, like other federal agencies, has accepted this status quo for decades. **Today, however, as an agency with a stated commitment to becoming a leader in anti-ableist research, NIDILRR cannot condone the government’s refusal to gather and use zip code level data to improve the lives and equal opportunities of people with significant expressive communication disabilities.**

¹² CommunicationFIRST & DREDF, *AAC Counts*, <https://communicationfirst.org/aac-counts/>.



We strongly urge NIDILRR and the Administration on Community Living (ACL) to explicitly reject this practice and to begin conversations among its federal partners, the disability and aging communities, and other stakeholders that identify and spur actions to remedy what we regard as a grave injustice perpetrated by the federal government that will worsen as long as it is permitted to endure.

B. All Ages (page 4)

CommunicationFIRST strongly supports NIDILRR’s demonstrated commitment to ensuring all of its R&D efforts are centered around the “whole person” and the real people we truly are, and are designed to collectively improve the lives and futures of all people with disabilities from the youngest to the oldest. **We strongly urge NIDILRR to solicit and fund participatory action R&D projects that address the following:**

- The fact that the need for a person to access and use AAC can occur at any point in their lifetime.
- The fact that research suggests that systemic oppression means Black and other multiply marginalized persons may be more likely to acquire this need as adults.
- The fact that all people who need AAC are at significant risk of being denied it, institutionalized, socially isolated, and subjected to intersectional oppression as soon as the need arises throughout their lives.

R&D efforts are vital to identify the reasons why these dynamics exist and the consequences as well as promising practices that exist here and internationally that can help disrupt and end the extreme oppression our members endure.

C. Models of Disability (page 4)

CommunicationFIRST vigorously applauds NIDILRR for its hard-won efforts to forge a new paradigm: A new way of understanding and living with disability as a natural part of the human experience. By requiring the research it funds to actively “explore the dynamic interplay between people and the enabling or disabling environments in which they live,” NIDILRR continues to transform the landscape and every facet of American life. As the draft plan correctly asserts:

(F)ocusing research on the whole person functioning in an environmental context, the new paradigm create(s) new opportunities for research toward



the removal of environmental barriers; provision of services, supports, accommodations, and technologies; and design of enabling policies.

We emphatically support this approach and desperately want more of this research to be carried out. Because the hard fact of the matter is that, with notable exceptions, far too little of this research is being done with regard to and in partnership with people who need AAC. **In fact, we believe the relative paucity of this type of research that relates to real-life experiences serves to perpetuate the disparities, dilemmas, and despair we endure. We implore NIDILRR to make changes in the final plan to address this void and the noxious vacuum it permits to exist.**

D. [Becoming a Leading Edge Anti-Ableist Research Enterprise \(page 5\)](#)

CommunicationFIRST believes that the task that NIDILRR is setting for itself of steadily becoming a credible leading-edge anti-ableist organization is imperative and achievable, and we stand ready to help advance and attain that goal. Ableism and intersectional discrimination manifest in different ways based on an array of factors. A predominant manner in which it presents itself and oppresses people who require AAC to express ourselves and be heard is what we refer to and define as “speechism”:

Speechism is prejudice and discrimination that occurs when a person or a group is discriminated against, stigmatized, treated unfairly and/or deemed inferior because their language, use of language, and/or means of expression is judged to be “unintelligible” or “inferior.” It can occur based on a person’s race, disability, ethnicity, primary language, use or non-use of spoken language, accent, preferred means of expression, or other factors. Speechism happens when someone’s use and understanding of language is derisively viewed due to being “foreign,” impossible to understand, or completely absent. Factors such as accent, vocabulary, syntax, style, rhythm and flow, or type of speech, such as oral speech versus synthesized or signed speech, can also come into play.¹³

CommunicationFIRST believes R&D efforts focused on better understanding and combating speechism are vital and can aid in identifying strategies for conducting disability justice research that is readily generalizable across many different topics. We strongly urge NIDILRR to solicit and fund such research.

¹³ CommunicationFIRST, “What Is Speechism?” (Dec. 16, 2022), at <https://communicationfirst.org/what-is-speechism/>.



E. Disability Language (page 6)

CommunicationFIRST is deeply appreciative that NIDILRR has repeatedly stressed in this plan and elsewhere that the use of terms like “nonverbal” and “noncommunicative” to describe people who require AAC are ableist, derisive, and stereotyping. Such terminology often is used to justify discrimination against and the exclusion of such individuals from everyday life. **We urge NIDILRR to support research that examines both the use and the impacts of various terms to describe people who need AAC, including the extent to which such terms are used to describe people who live in isolated versus integrated settings.**¹⁴

F. NIDILRR Aims (page 6)

As noted above, we believe it is important to use the research of today and tomorrow to question, disprove, and reject past research findings that are erroneous, biased, and discriminatory. This is especially critical when such past research is relied upon to legitimize widespread disability-based discrimination. For example, children who require AAC but lack access to it are routinely subjected to standardized IQ assessments when they begin school, usually at age 2 or 3, even though they have no means to respond to the questions. Such tests have been shown to be racially, disability, culturally, and linguistically biased. **CommunicationFIRST calls on NIDILRR to make clear in the final plan that generating new knowledge that debunks ableist and intersectional oppression is among its more important aims.**

G. NIDILRR Collaborations (pages 6 and 7)

One of the most powerful tools NIDILRR has to further its mission is its relationships and strategic partnerships with its fellow federal agencies. NIDILRR now has formal working partnerships with several agencies and research units, including five institutes of the National Institutes of Health (NIH). CommunicationFIRST is concerned that the National Institute on Deafness and Other Communication Disorders (NIDCD) is not one of them. We already have shared this concern with NIDCD. Moreover, we have conveyed to NIDCD that we believe it is both highly beneficial and imperative for the two to develop a strong, effective, and enduring research partnership.

¹⁴ CommunicationFIRST, “The Words We Use” (July 11, 2023), at <https://communicationfirst.org/the-words-we-use/>.



NIDILRR and NIDCD have very different missions and rely on very different research paradigms, methodologies, tools, and networks to conduct their work and achieve their aims. Yet each shares a common ultimate customer, and we believe these are customers who continue to be objectified, subjectified, and never heard. From a research perspective, we believe that in order for people with communication disabilities to be heard and respected, federal research agencies must actively reach out to and effectively engage with a wide and diverse range of individuals who need AAC – particularly those who are most often denied it – as equal partners in every facet of research related to AAC and the health and well-being of those who need it.¹⁵

NIDILRR, NIDCD, and most importantly, our members would benefit greatly from the two research enterprises prioritizing and sponsoring a series of participatory research, capacity-building, and development activities, including ones that expose and combat ableism and intersectional oppression. **For these reasons, CommunicationFIRST calls on NIDILRR and NIDCD to develop and engage in a strong strategic partnership as soon as possible in order to forge a joint set of research priorities and activities, including through co-funding when possible.**

H. Proposed New Emphases

Emphasis 1: NIDILRR will strive to be a leader as an anti-ableist research organization.

In April 2022, CommunicationFIRST submitted comments and recommendations to NIH on its Proposed Framework for the NIH-Wide Strategic Plan for Diversity, Equity, Inclusion, and Accessibility (DEIA).¹⁶ We believe most, if not all of the advice we offered the NIH can be useful to NIDILRR in advancing its stated aims. We are attaching it and hope that NIDILRR will review it and find it beneficial.

Emphasis 2: NIDILRR will encourage and expand opportunities for inclusion of people with disabilities across the research enterprise with intentional strategy and operationalization.

¹⁵ See CommunicationFIRST, “Comments to the NIDCD on Priorities for Research on AAC and People Who Use AAC” (Sept. 15, 2023), at <https://drive.google.com/file/d/17ou6nNrMNFMMVSLakkBTMJ1nuqD8Qzly/view?usp=sharing>.

¹⁶ CommunicationFIRST, “Comments and Recommendations on the Proposed Framework for the NIH-Wide Strategic Plan for Diversity, Equity, Inclusion, and Accessibility” (Apr. 3, 2022), at https://drive.google.com/file/d/18V3ga46ZzsfF2bWUpKilHKhLPu9_bmnY/view?usp=sharing.



Please see the Attachment and preceding comment above.

Emphasis 3: NIDILRR will encourage the adoption of innovative research approaches.

CommunicationFIRST strongly urges NIDILRR to intentionally invite R&D applications that use innovative research approaches from organizations that are majority-controlled, directed, and staffed by people with disabilities, and to assist them to team up with researchers with and without disabilities upon request.

We want to point out that predictive modeling research and practices have and will likely continue to result in a range of positive to adverse consequences for people with and without disabilities who are who are multiply marginalized. We believe people who require AAC are among those with the greatest to gain or lose in this regard. It is crucial that NIDILRR explicitly address these tensions.

Emphasis 6: NIDILRR will build its portfolio of international R&D activities.

CommunicationFIRST wants to point out that several nations that are signatories to the UN Convention on the Rights of People with Disabilities are using the CPRD as a framework for creating and strengthening cultural expectations, policies, practices, and programs in ways meant to enhance communication access and the everyday lives of people who need AAC. **Research is needed to better understand the effectiveness of these efforts and to determine to what extent it would be feasible and productive to replicate such activities in the U.S.**

Emphasis 7: NIDILRR will invest in research projects across its entire portfolio that intentionally include populations of people with disabilities with the greatest support needs.

The vast majority of CommunicationFIRST’s members are “people with disabilities with the greatest support needs.” Even with the dearth of available demographic data noted above, evidence strongly suggests that the majority of our members have their most basic needs go unmet, their abilities dismissed, and their civil rights and civil liberties evaded and eviscerated. Most are prevented from enjoying the post-ADA / post-*Olmstead* world that supposedly exists. Their lives are far more proscribed due to status quo prejudices and “doing things as they have always been done.”

Consequently, the need for comprehensive, longitudinal, qualitative and quantitative R&D activities that document the state of people who need AAC in the U.S. is urgent



and tremendous. As a first step toward developing a clear vision and plan for carrying out such an effort, CommunicationFIRST urges NIDILRR to host a series of listening sessions to solicit the views and ideas of AAC users, families, advocates, researchers, and others on pressing issues and questions that most need to be explored and addressed.

Emphasis 8: NIDILRR will invest in research projects across its entire portfolio that have an intersectional focus.

CommunicationFIRST believes this investment in and focus on intersectionality is indispensable and far overdue. CommunicationFIRST members who are Black, indigenous, people of color, and non-English-using who need AAC face enormous barriers obtaining it and greater oppression because of it.¹⁷ **We strongly urge NIDILRR, ACL, their grantees, and federal partners to conduct R&D efforts designed to identify the root causes of this intersectional discrimination, and promising practices that may be useful in redressing them.** In particular, we urge NIDILRR to:

1. Fund a meta-analysis and other R&D activities that collate and build on the existing literature on:
 - a) Why Black people with disabilities and other multiply marginalized individuals may be more likely than whites to acquire the need for AAC at some point in life;¹⁸ and
 - b) The types and impacts of intersectional oppression such persons endure.
2. Intentionally invite R&D applications that use organizations that are majority-controlled, directed, and staffed by people with disabilities and to assist them to team up with researchers with and without disabilities from Historically Black Colleges and Universities and similar institutions of higher learning.

¹⁷ Pope, L., Light, J., & Franklin, A. (2022). Black children with developmental disabilities receive less augmentative and alternative communication intervention than their white peers: Preliminary evidence of racial disparities from a secondary data analysis. *American Journal of Speech-Language Pathology*, 31(5), 2159–2174. https://doi.org/10.1044/2022_AJSLP-22-00079

¹⁸ See, e.g., Black, L. I., Vahratian, A., & Hoffman, H. J. (2015). *Communication disorders and use of intervention services among children aged 3–17 years: United States, 2012* (Data Brief No. 205). National Center for Health Statistics. <https://www.cdc.gov/nchs/products/databriefs/db205.htm>



Emphasis 9: NIDILRR will invest in research projects that focus on children and youth with disabilities.

We are painfully certain that the greatest risks and unmet needs infants, toddlers, students, and transition-age young people who need AAC experience are not reflected in data collection and analysis. Because neither the U.S. Department of Education nor any school system gathers any data specific to these children and young people, we have no firm understanding of what their educational experiences and outcomes look like. What we know based on available information is horrifying and inexplicable. It is reported that over 90 percent of students who need AAC leave school reading at or below a second grade level. Similarly, over 90 percent of nursing home residents under age 19 are reported to have expressive or receptive communication disabilities.¹⁹

We make the same recommendation as we did above: The need for comprehensive, longitudinal, qualitative and quantitative R&D activities that document the state of people who need AAC in the U.S. is urgent and tremendous. As a first step toward developing a clear vision and plan for developing and carrying out such an effort, CommunicationFIRST urges NIDILRR to host a series of listening sessions to solicit the views and ideas of AAC users, families, advocates, researchers, and others on pressing issues and questions that most need to be explored and addressed.

Emphasis 10: NIDILRR will invest in research projects that focus on adults aging with disability.

We make the same recommendation with regard to working age and older adults who need AAC and we do for the same reason: We need basic demographic data on such individuals in order to understand and enhance their lives.

Thank you for your consideration of these comments.

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ATTACHMENT

CommunicationFIRST, Comments and Recommendations on the Proposed Framework for the NIH-Wide Strategic Plan for Diversity, Equity, Inclusion, and Accessibility (DEIA) (Apr. 3, 2022), at https://drive.google.com/file/d/18V3ga46ZzsfF2bWUpKilHKhLPu9_bmnY/view?usp=sharing.

¹⁹ Ne’eman, A., Stein, M., & Grabowski, D. C. (2022). Nursing Home Residents Younger than Age Sixty-Five Are Unique and Would Benefit from Targeted Policy Making. *Health Affairs*, 41:10, 1449-1459. <https://doi.org/10.1377/hlthaff.2022.00548>.

ATTACHMENT



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Because communication is a human right.

CommunicationFIRST Comments and Recommendations on the Proposed Framework for the NIH-Wide Strategic Plan for Diversity, Equity, Inclusion, and Accessibility (DEIA)

April 3, 2022

<https://grants.nih.gov/grants/guide/notice-files/NOT-OD-22-061.html>

Objective 1: Implement Organizational Practices to Center and Prioritize DEIA in the Workforce

NIH WORKFORCE

CommunicationFIRST is the nation's only human and civil rights organization led by and for the estimated five million people in the United States who need methods other than natural speech to express ourselves. The tools and support we use are referred to as augmentative and alternative communication, or AAC. 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, we encourage NIH to:

- (1) Survey its workforce to determine what percentage of its employees currently use AAC, as well as to gather information on their characteristics, careers, and aspirations;
- (2) Seek the advice and insights of these NIH 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 and others who have relied on AAC in their work; and

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(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.

WORKFORCE AT INSTITUTIONS SUPPORTED BY NIH FUNDING

Over the last decade, less than 2% of NIH-funded researchers reported having a disability. Statistics like this reflect deep-rooted biases and unwarranted assumptions. They also raise disturbing questions as to such grantees' and contractors' compliance with the Rehabilitation Act's nondiscrimination and affirmative action provisions for individuals with disabilities under Sections 504 and 503. The lack of disability diversity across this group of researchers who are looked to as on the cutting edge in their fields also poses barriers to creating the diversity of perspective and experience that NIH views as integral to its mission and to conducting world-class research. NIH must invest considerable leadership efforts and resources in remediating these flaws. It should require and provide technical assistance and support to its research networks to carry out actions that are similar to the ones outlined above. Under Section 503, NIH-supported initiatives also must take affirmative action to employ individuals with targeted disabilities, including those who rely on AAC for speech-related disabilities.

Objective 2: Grow and Sustain DEIA through Structural and Cultural Change

More than other populations, people with disabilities can experience either significant benefits or devastating harms from biomedical research. This is especially true for people who must rely on augmentative and alternative communication (AAC) due to speech-related disabilities. Both due to the paucity of NIH researchers with disabilities, and the fact that we are rarely if ever, are invited to help set research priorities, review and rank research proposals, serve as active participants rather than "research subjects," or otherwise be seen as having rich lived experience, underscores the tremendous work that must be done on these fronts.

To be effective in ameliorating these shortcomings that, if left untreated, will undercut its efforts to promote and strengthen a true enterprise-wide DEIA culture, NIH should partner with the disability community to identify the factors



that contribute to this lack of representation and the actions that must be taken in order to reverse it.

The NIDCD in particular should strengthen the methods it utilizes to seek, value, and incorporate the insights as well as lived and professional expertise of people who require AAC at all stages of the research process. This includes their meaningful participation in setting research priorities, reviewing and rating proposals, co-designing and leading research projects, serving as active participants rather than just research subjects, as well as evaluating and critiquing research results.

To be successful at all this, NIDCD and NIH must become leading practitioners and proponents of participatory action research.

Objective 3: Advance DEIA Through Research

WORKFORCE RESEARCH

The comments and recommendations above should be designed, implemented, evaluated, and continuously refined. We recommend that NIH undertake a comprehensive review of the research it has engaged in and funded that is participatory action research-driven.

HEALTH RESEARCH

It is imperative that people who need AAC be meaningfully engaged in every facet of research related to AAC and the health and well-being of those who need it. We are painfully aware that most people with speech-related disabilities who need AAC continue to be denied meaningful access to the communication tools and supports they need to be understood. We believe it is critical that people who use AAC today be engaged in all research affecting individuals who lack it. NIH must assure this because failure to do so deprives those who most need it of the benefits of the perspectives of those who most understand what it is like not to be understood by others and the terrible consequences that result.

Additional research is critically needed in the following areas:



(1) Improving the collection, analysis, and reporting of demographic data on people who require AAC. Currently there is no comprehensive data on this population in the United States. Being understood is an essential indicator of an individual's health and well-being. NIH must take the lead in closing this gap.

(2) Identifying and ameliorating the factors that result in people from racial, linguistic, and other minority communities being both more likely to have developmental and acquired disabilities that may make their use of AAC necessary and to face greater bias in accessing it. Limited research has been done on the reasons this is true or how to remedy the problem. More research on reducing these disparities is vital.

(3) Ensuring “just in time” access to AAC. Researchers 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 support to communicate, and then are blamed for not having the capacity to learn to communicate using language. Additional research is needed to take these methods to scale and make them universally and equitably available.

Finally, we call on NIH to stop funding research that relies on methods that 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 “intellectual ability” assume the person can either speak or move their bodies in intentional ways. NIH cannot continue to subsidize research that uses biased methods with lifelong discriminatory impacts. Doing so is almost certainly a violation of the Hippocratic Oath to “do no harm.”



CommunicationFIRST

Because communication is a human right.

ADDENDUM to CommunicationFIRST's Comments to NIDILRR on its Draft 2024-2028 Long-Range Plan Regarding New Research Activities

Submitted **October 31, 2023**, to NIDILRRFuture@neweditions.net

As a follow-up to the [comments](#) CommunicationFIRST submitted to the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) on October 13, 2023, we offer the following additional comments and recommendations on NIDILRR's proposed priority research activities in its [Draft 2024-2028 Long-Range Plan](#) (LRP). The October 13 comments focused mainly on pages 1-16 of the LRP; these comments focus primarily on pages 17-30. Please do not hesitate to contact Bob Williams, Policy Director, at info@communicationfirst.org, with any questions on or additional information about these comments.

I. Proposed New Community Living and Participation Research Agenda

CommunicationFIRST strongly supports the prospects of NIDILRR funding research on how Section 504 currently impacts and should affirmatively impact school as well as lifetime outcomes of students with disabilities. We also support NIDILRR's stated intent to remedy the lack of research on how students who have Section 504 plans fare in school, at transition age, and as adults.

However, we must point out another research gap that is critical for NIDILRR to consider and address. To our knowledge, no federal agency, including the US Department of Education and NIDILRR, has funded or sponsored much research specifically on the demographics or educational experiences/outcomes of students who require augmentative and alternative communication (AAC). As we stated in our October 13 comments, there are notable exceptions to this assertion that should be built upon. This said, the bottom line is that we need research to provide a clear picture of how these youth are faring in terms of:



- The number, percent, demographics, and characteristics of students in the US who need AAC who have an IEP or Section 504 plan in terms of who has – and who does not have – meaningful access to AAC.
- Disability characteristics – what disabilities, degrees of disabilities, and health conditions affect them.
- The extent to which these students are being denied access to AAC based on biased standardized IQ assessments, unwarranted assumptions, or other discriminatory methods/practices, biased research findings, or because “it has always been done this way.”
- Whether such students spend their school day in inclusive or segregated settings.
- Whether such students have access to the general curriculum, graduate from high school, drop out, or receive a certificate of completion.
- Information on how these students participate in or are excluded from their school environments and what the barriers to or facilitators of a positive social experience in their schools include.
- And more that would be happy to expand on.

CommunicationFIRST strongly urges NIDILRR to work with the Department of Education, the National Institute on Deafness and Other Communication Disorders (NIDCD), people who use AAC, families, the disability community, state and local educational agencies, and others in every facet of this research. To be effective, we believe such research should be carried out in diverse school systems of different sizes, as well as at statewide and national levels.

NIDILRR is correct, of course, to point out that “schools are a primary community in which children with disabilities spend their time.” Yet students who need AAC continue to be disproportionately exiled to and “educated” in separate schools and residential institutions. Local and state education agencies as well as state and local governments as a whole have federal civil rights obligations under the Civil Rights Act and Section 504 of the Rehabilitation Act that bar them from discriminating on the basis of race, gender, disability, creed, ethnicity, language, or other protected class status. These laws must be effectively implemented and fully enforced beyond the proverbial schoolhouse door. State Medicaid agencies in particular play a key role in the educational, community living, and



health experiences and outcomes of the more than one million infants, toddlers, school students, and transition-age young people with disabilities who are covered by their state's Medicaid or Children's Health Insurance Program (CHIP).

There is little to no research or understanding on how variations in how states administer these programs facilitate, hinder, or prevent inclusive schooling, integration, community participation, effective communication, safety, health, and well-being of youth who need AAC, and disabled youth in general. CommunicationFIRST therefore strongly urges NIDILRR to fund research on:

- Variations in states' Medicaid and CHIP programs' assessment, coverage, and related policies and practices with regard to the financing of:
 - A) AAC tools, strategies, and supports for infants, toddlers, students, and transition-age youth with disabilities, and
 - B) youth placement in segregated "residential schools," nursing homes, Intermediate Care Facilities for Individuals with Intellectual Disability (ICF/ID), inpatient psychiatric facilities, and other institutions.
- The impacts – good, bad, and ugly – such policies and programs have on young people with significant communication and other disabilities.

The rights, needs, and accommodation requirements of those with significant expressive communication disabilities are the same as or similar to those with other disabilities. However, our specific communication needs, rights, and accommodation requirements are ignored in life, research, and policies and practices. This is most often true in situations:

- When the need for effective communication is vital, including in life and death situations;
- That involve strangers whose role it is to understand and assist us;
- In environments that we are not typically seen in; and/or
- Where matters are complex, in flux, and may pose opportunities or threats.



NIDILRR makes clear it will fund research in the following three areas of major import to people with disabilities, including people who require AAC to express ourselves and to be treated equitably:

- Gaining a better understanding of the effects climate change on people with disabilities;
- Enhancing inclusive emergency preparedness and response practices and outcomes; and,
- Advancing full access to air travel and other modes of transportation.

Each of these research programs involves the types of situations and tensions we just outlined. **CommunicationFIRST, therefore, strongly urges that people who need AAC, our families, organizations, and allies be effectively engaged in every phase, facet, and role affecting such research, including as co- and principal investigators.**

II. Proposed New Health and Function Research Priorities

The ability to use spoken, signed, and written language is said to be the essence of our shared humanity. It is certainly imperative for health and well-being. Indeed, being recognized and treated as individuals who use and understand language is a vital social determinant of health. In stark contrast, people who have little to no speech that others can understand are nearly universally branded as “deficient,” or void of the ability to communicate: To use words and sentences to make ourselves understood by others. Such ableism subjects many such individuals to being barred access to AAC, lifelong isolation, egregious discrimination, and substandard health care and health outcomes, among a great many other harms. Its ultimate consequences can be described as “social death,” regarded as and treated by most other people as well as the dominant culture, government, and society as:

- Incapable of effective communication;
- Socially detached;
- “Unintelligent”;
- Having no personal identity or agency; and



- Lacking the need and right to be treated as fully human.¹

The personal degradation, alienation, health disparities, and adverse health and life outcomes that our members endure are largely due to the fact that society's abject failure to understand us; somehow, this failure to understand us leads to proof positive of our assumed inferiority. As Kasnitz and Block (2012) report:

In oral history interviews with people with multiple impairments from cerebral palsy, including the inability to walk, transfer at all alone, or use their arms or hands, the experience of speech impairment consistently is their biggest concern and source of pain.² (Emphasis added.)

CommunicationFIRST believes the same is true with regard to the vast majority of children, youth, working age, and older persons who need AAC to express ourselves and to lead our lives.

More than sources of fleeting concern and pain, these forces are a constant threat to our holistic health and well being, effective communication, societal acceptance and participation, and to our very lives.³

For these and numerous additional reasons, CommunicationFIRST calls on NIDILRR to fund a Model Systems program focused on the estimated 5 million people who need AAC. The Model Systems program would center on:

¹ Borgstrom, E. (2017). Social Death, *QJM: An International Journal of Medicine*, 110(1): 5-7, <https://doi.org/10.1093/qjmed/hcw183>; Deborah C. Reidy, [Stigma is Social Death: Mental Health Consumers/Survivors Talk About Stigma In Their Lives](#), Alaska Mental Health Consumer Web; [Family and Psycho-Social Dimensions of Death and Dying in African Americans](#), Key Topics on End-of-Life Care for African Americans, Duke Institute on Care at the End of Life and the Initiative to Improve Palliative Care for African Americans.

² Kasnitz, D., & Block, P., [Participation, Time, Effort, and Speech Disability Justice](#), p. 197, Academia.edu; Kasnitz, D., & Block, P. (2012). Participation, Time, Effort, and Speech Disability Justice, Ch. 14, in *Politics of Occupation- Centred Practice: Reflections on Occupational Engagement Across Cultures*. DOI:10.1002/9781118702819.CH14.

³ [Kids Need to Be Able to Communicate with their Doctors | CommunicationFIRST](#), 2022; [CommunicationFIRST Asks White House to Improve Communication Equity | CommunicationFIRST](#), 2021; and [How Are Disabled People Affected When COVID-19 Health Care Rationing Happens?: NPR](#), 2020.



- Identifying, elevating, and measurably enhancing the communicative, educational, health and wellness, integrated living, and socio-economic prospects and outcomes of all such persons.
- Developing strategies and partnerships at the community, state, and national levels to lessen and eliminate the health disparities, discrimination and social death of people who require AAC, especially by those that are institutionalized and/or multiply marginalized.
- Developing, testing, and fielding survey questions and other methods for collecting local, state, and federal data on the number, characteristics, and unmet needs of people who need AAC of all ages living in community, group living, congregate, and institutional settings.
- Partnering with all HHS components to develop and carry out R&D and related activities designed to enhance the lives, health, well being, community living, and human and civil rights of the estimated 5 million people with speech-related communication disabilities in the U.S.
- Assisting other federal and their grantee networks and contractors to do the same.
- Identify, develop, elevate, strengthen, model, and demonstrate the need for and efficacy of participatory action research/practice and the enhanced real life outcomes it can spur.

CommunicationFIRST envisions this proposed model systems program to be demonstratively conceived, managed, and led by a genuine collaborative made up of a non-mutually exclusive leadership team of individuals who express ourselves via AAC; other people with disabilities; our families and allies; researchers; clinicians; and others.

The central aim of the program would be to expose, disrupt, and work to eradicate the harm that racism, ableism, speechism, and additional co-occurring oppression inflict on our members, families, allies, and direct support professionals. For these reasons, we strongly recommend that the proposed model systems' leadership team, staff, and advisors be made up by at least 51 percent of individuals who need AAC and those who are Black, indigenous, people of color, and other multiply marginalized individuals.



II. Proposed New Spinal Cord Injury Research Priorities

An unknown number of children, youth, working age and older persons with spinal cord injuries and other forms of functional paralysis need AAC. While some research exists on this cohort, we believe more focused efforts are critically needed.

We, therefore, urge NIDILRR to intentionally solicit and support additional R&D activities that:

- Document the ways and extent to which they experience barriers to AAC, segregation, institutionalization, unjustified isolation, and intersectional discrimination.
- Identify, develop, and promote evidence-informed policies and practices that can help disrupt, prevent, and remediate such discrimination.

CommunicationFIRST further recommends that similar research be done with regard to people who experience traumatic brain injury (TBI) as well as others who need AAC.

III. Proposed New Employment Research Priorities

The vast majority of young people, working age, and older adults who need AAC experience lifelong joblessness and are instead subjected to segregated Medicaid-funded day programs, subminimum wage employment, unjustified isolation, learned helplessness, and social death. **CommunicationFIRST, therefore, strongly urges that people who need AAC, our families, organizations, and allies be effectively engaged in every phase, facet, and role affecting such research including as co- and principal investigators.**

IV. Proposed New Communication Technology Priorities

The self-evident truth of the ADA is that all people with disabilities have the right to belong to and be treated as equals in American society. Assuring digital access and inclusion is paramount to achieving this vital national goal. Upon signing the ADA into law, President George H.W. Bush declared to the nation that it was well past time for the “shameful wall of exclusion (to) finally come tumbling down.” Over a generation later, much progress has been made in achieving this aim. But far more remains to be done.



The walls of digital exclusion are just as high, impenetrable, and life-robbing as those that existed in 1990. This is true for millions of people with and without disabilities, and we believe it is particularly true with respect to our members.

For the extremely few of us who can use speech generating devices as well as the Internet, websites, email, and platforms like Zoom, the results often are positively transformative. But most people who need AAC – regardless of whether they have access to it – have no or meager access to websites, apps, digital content, or other information and communications technology (ICT). **As a direct consequence, our members are not only “detached” from the community, from what is taking place, and being made possible online. They will also increasingly be made even more invisible, personally and politically powerless, and disposed of by society even more than today.** This status quo must be upended.

CommunicationFIRST, therefore, strongly urges that:

- **NIDILRR actively solicit and support R&D efforts to disrupt R&D in ways that bring about greater digital accessibility, inclusion, and equity for all people who need AAC.**
- **NIDILRR strongly encourage, incentivize, and require that people who need AAC, our families, organizations, and allies be effectively engaged in every phase, facet, and role affecting such research including as co- and principal investigators.**

V. Proposed New Disability Statistics and Demographics Research Priorities

For purposes of clarity and consistency, and to emphasize the importance we assign to this matter, we will restate our October 13 comments and recommendations on this point:

NIDILRR defines its target population as encompassing those with “developmental, cognitive, sensory, psychiatric, and physical disability.” This has been the longstanding practice throughout the government and largely tracks the six disability classes that the U.S. Census Bureau and federal statistical agencies use to determine what cohorts of people with what specific disabilities count and deserve



to be counted, and which of us should continue to be uncared, go unheard, and subjected to egregious discrimination that goes unnoticed.

We strongly urge NIDILRR to explicitly include “communication disability” as a target population in its final plan and to use its prestige and relationships to convince other federal agencies, including statistical agencies, to take similar actions discussed below. As CommunicationFIRST and the Disability Rights and Education Defense Fund (DREDF) document in *AAC Counts: The Urgent Need for Better Data About People with Significant Speech Disabilities*:

People in the United States who cannot rely alone on speech to be heard and understood are not counted in any systematic manner by federal or state governments. Failing to accurately track our characteristics, access to services and supports, and unmet needs makes it impossible for policymakers and advocates to appreciate and address the challenges, barriers, and intersectional discrimination we grapple with each day.⁴

Some data is periodically gathered on people with expressive communication disabilities in the National Health Interview Survey (NHIS) and Survey of Income and Program Participation (SIPP). However, none of this data can be used to produce zip code, community, or even state-level estimates and insights. Such data also fails to identify or provide any information at all about the demographics, integration, participation, segregation, or unmet needs of people in this country who require AAC. NIDILRR, like other federal agencies, has accepted this status quo for decades. **Today, however, as an agency with a stated commitment to becoming a leader in anti-ableist research, NIDILRR cannot condone the government’s refusal to gather and use zip code level data to improve the lives and equal opportunities of people with significant expressive communication disabilities.**

We strongly urge NIDILRR and the Administration on Community Living (ACL) to explicitly reject this practice and to begin conversations among its federal partners, the disability and aging communities, and other stakeholders that identify and spur actions to remedy what we regard as a grave injustice

⁴ CommunicationFIRST & DREDF (2023), *AAC Counts*, <https://communicationfirst.org/aac-counts/>.



perpetrated by the federal government that will worsen as long as it is permitted to endure.

VI. Proposed New ADA National Network Priorities

Following the release of both the 1977 HEW Section 504 rule and later the ADA rules, NIDILRR and several other federal agencies funded efforts to provide technical assistance to individuals with disabilities, their families, and covered entities on the regulations and ways to implement them. This was done in recognition of the tremendous good these rules do for people with disabilities and the entire country and the importance of getting their implementation right. These efforts also were instrumental in fostering collaborative problem-solving and implementation efforts among all parties. We believe that efforts by Congress, the Federal Communications Commission, and others centered on making all ICT readily accessible and useful to all people with disabilities give rise to yet another series of teachable moments.

We, therefore, urge NIDILRR to ensure the ADA Network prioritizes and ramps up technical assistance efforts centered on the challenges, opportunities, and threats presented by digital accessibility and artificial intelligence to people who need AAC.

* * *