



Communication**FIRST**

Because communication is a human right.

Communication Equity Call to Action for the Biden-Harris Administration

January 14, 2021

CommunicationFIRST and the 47 undersigned supporters of communication rights, access, and equity urge the incoming Biden-Harris Administration to take immediate and specific steps to safeguard and advance the human and civil rights of people with disabilities, especially individuals who have little to no understandable speech and rely on augmentative and alternative communication (AAC). Children, working age, and older people with significant communication disabilities have always been among the most marginalized in our society.

The pandemic and racial disparities are threatening the health and lives of these persons in an unparalleled manner. Individuals who require AAC are often institutionalized, isolated, immunocompromised, and wrongly regarded as lacking in the capacity, need, or right to communicate and make decisions about their lives. This has been found to be endemic in health care contexts; see, for example, [here](#), [here](#), and [here](#). Furthermore, Black Americans and other people of color are more likely to experience stroke, ALS, Parkinson's, and other conditions that may require them to use AAC. Research also indicates that individuals who belong to racial, ethnic, and linguistic minority communities who need AAC frequently face added difficulties in obtaining it; see, for example, [here](#), [here](#), and [here](#). We must not allow such injustices to linger, especially at this time.

We strongly urge the administration to act on the following nine steps in its first six months, by no later than July 26, 2021, the 31st anniversary of the Americans with Disabilities Act (ADA).

1. Investigate and prevent health care discrimination against people with communication disabilities.

The Departments of Justice (DOJ) and Health and Human Services (HHS) must investigate the death of [Sarah McSweeney](#), an AAC user who died in an Oregon hospital [reportedly](#) in significant part due to the blatant biases of members of her medical team and their judgment that her life was not worth saving. The investigation should make an explicit finding on whether her civil rights were violated and if so, what enforcement actions will be taken. The agencies should also announce the steps they will each take to help prevent future egregious discrimination and the taking of disabled lives. The President should issue the directive to investigate immediately upon taking office and the



investigation's findings and consequent enforcement and policy recommendations should be made public within 180 days.

2. Assure the effective communication rights of children and adults with speech-related disabilities, especially in public health emergencies.

The Departments of Justice, Health and Human Services (HHS), and Homeland Security (DHS) should develop and issue joint guidance to clearly delineate the effective communication rights of individuals with expressive disabilities, including those that rely on AAC, tailored to the missions, authorities, and responsibilities of all three agencies. Most federal guidance on effective communication to date has focused on the first two types of communication disabilities – vision and hearing – while neglecting by comparison the third type relating to speech. This lack of specific guidance has created obstacles to ensuring civil rights protections of people who cannot rely on speech to be understood. This has proven especially challenging during the pandemic.

DOJ should take the lead on this effort because of the coordination role it plays in the consistent enforcement of the ADA and Section 504 of the Rehabilitation Act across the federal government. It is also crucial that HHS and DHS develop this joint guidance given the complementary roles both play in assuring the health, well being, independence, and security of all people particularly during the pandemic and other disasters and emergencies as well as the paramount role effective communication must play in such vital efforts.

This guidance should build on the [joint FAQs on effective communication issued in November 2014 by the Departments of Education and Justice](#) and should take effect no later than July 26, 2021. Additionally, since all other federal agencies have an obligation to comply with and enforce the effective communication requirements of ADA and Section 504, each should be directed to use it to develop guidance of their own.

3. Clarify the ADA's anti-discrimination, integration, and effective communication requirements for people with speech-related disabilities in all facets of life.

The civil rights guaranteed to individuals who rely on AAC under the ADA, Section 504, and the *Olmstead* decision are routinely ignored and violated in the best of times, resulting in such persons continuing to experience widespread isolation, abuse, neglect, and institutionalization, and extreme discrimination in communication access, education, health care, employment, and all other facets of life. The pandemic has only exacerbated these



injustices. It is critical that DOJ, in coordination with other federal agencies and stakeholders, develops and implements guidance, training, technical assistance, and other measures to clarify, stress, and emphasize to all covered entities what the ADA anti-discrimination, integration, and effective communication mandates mean for children as well as working age and older adults with significant expressive disabilities. The guidance and activities should be developed for, applied to, and carried out during both the pandemic and the post-pandemic era.

4. Guarantee equal educational access for students with significant expressive disabilities.

Despite progress in increasing equal and inclusive educational opportunities for individuals with disabilities from early intervention through post graduate studies, students who rely on AAC to be understood are still branded as “less than” from the start. They are assigned low expectations and assumed to be less likely to learn, less intelligent, less likely to communicate, and less likely to connect or to make a life for themselves. The President-elect knows first-hand what it is like to grow up with a speech disability and the importance of us all replacing the prejudices, discrimination, and dreams never lived with greater understanding, justice, and opportunities.

The Biden-Harris Administration should take several immediate actions to advance educational access and opportunities and outcomes for persons who use AAC throughout life:

- The Education and Justice Departments should offer information, training, and technical assistance to students with significant expressive disabilities, their parents, teachers, schools, state education departments, school districts, higher education institutions, and other stakeholders on the importance of ensuring effective communication in a range of educational contexts, and ways to comply with the communication provisions of the ADA, Section 504 of the Rehabilitation Act, and the Individuals with Disabilities Education Act (IDEA). The rights of individuals using AAC to enroll, attend, and have equal access to post-secondary, graduate, post-graduate, and other lifelong educational, employment, or other educational opportunities should be clarified.
- The Education and Justice Departments should immediately develop and issue joint guidance on the educational access and communication rights of students who use AAC during the pandemic. The guidance should be followed by training and technical assistance.
- The Education Department should review the extent to which Intelligence Quotient (IQ) tests and similar cognitive assessments are inappropriately used



with students with motor and speech disabilities, resulting in lifelong discriminatory and harmful effects, and determine appropriate short- and long-term actions to prevent and reverse their use and effects. The Education Department should also take action to ensure that actual or perceived intellectual disability is never used as a basis to deny a student access to AAC.

5. Ensure safe and equitable access to instruction during the pandemic.

Students who rely on AAC to be heard and understood generally have multiple co-occurring disabilities and health conditions that can affect learning, mobility, coordination, personal care, and physical and emotional needs. They therefore often require in-person assistance from an adult throughout the school day. They also face significant [increased risk](#) of both contracting and dying from COVID19. Entering group settings in school buildings before a vaccine is available for children significantly increases these risks. As a result, many AAC users for safety reasons must continue to be educated remotely. But because many school districts are denying AAC users the in-person support they need to access virtual learning, they are effectively shut out of the same educational opportunities being provided to students without disabilities.

On January 4, 2021, CommunicationFIRST released the [results of a national survey](#) of families about student experiences attempting to access safe instructional opportunities during the pandemic. We learned that while many students are being denied access to the supports they need to safely access virtual instruction from home, more than a dozen school districts in nine states have figured out a way to comply with the ADA and to safely provide in-person aides to support these most vulnerable students from their homes or elsewhere, to ensure they have equal access to the same educational opportunities being provided to nondisabled students throughout the pandemic.

The Biden-Harris Administration must make the issuance of such guidance and the provision of related training and technical assistance one of its highest priorities. No student should be [forced to choose between](#) avoiding COVID19 health risks and receiving basic access to educational opportunities.

6. Stress and invest in lifelong literacy learning and success.

Educational and career success requires effective communication. Communication is generally most versatile, flexible, and effective in those settings when expressed with *language*. The majority of what people wish to communicate in sign, spoken, and written language is spontaneous and cannot be adequately conveyed in one word or stock phrases. To be understood, those



that use text-based AAC must literally spell out most of what they say each day. It is imperative, therefore, that these children and adults are afforded the opportunities, tools, and support they need to learn, strengthen, and use optimal literacy skills at every stage of their life. Its development must begin at a young age and continue throughout life and is pivotal to our humanity. AAC, American Sign Language, Braille, plain language, technology and other accommodations make it possible for all people to communicate as never before. Yet, far too many who need AAC lack it and are consigned to lifetimes incommunicado. Urgent actions to end this vicious cycle must begin now.

Accordingly, the Education Department should work with other federal agencies, persons with significant expressive disabilities, families, teachers, states, school districts, higher education, foundations, and experts in AAC, lifelong literacy learning, aging, health care, and other providers to develop a national strategy for identifying the causes, effects, and extent of this discrimination and taking short- and long-term actions to combat it by creating greater equality of opportunity for people with significant communication disabilities.

7. Remove bureaucratic barriers under Medicare and Medicaid that deny people with disabilities access to the AAC they need to communicate.

Children and adults with significant expressive communication disabilities and their families experience enormous barriers and hardships in obtaining necessary AAC assessments, devices, and services in typical times. COVID19 has made matters even worse. The Centers on Medicare and Medicaid Services (CMS), for example, has refused to respond to calls from CommunicationFIRST and other organizations to permit Medicare to pay for telehealth assessments to determine whether beneficiaries' accessing a speech generating device is a "medical necessity." In other words, Medicare is insisting that such evaluations take place only in-person, requiring people with disabilities to choose between risking their lives and forgoing communication. This policy, coming from an agency charged with ensuring improved health of Americans, is both incomprehensible and unconscionable. In another bureaucratic nightmare, according to press reports, the [Arizona Medicaid program](#) instituted a practice over a year ago to automatically deny claims to pay for communication devices.

CommunicationFIRST and the undersigned organizations are deeply concerned by these incidents and the biases and discriminatory attitudes that undergird them. We fear that other public and private insurers have similar policies and practices in place already or might institute them in the future if no action is



taken. To unjustly deny anyone their ability and right to express themselves subverts our nation's creed.

The HHS Secretary should immediately direct CMS to reverse Medicare's refusal to pay for telehealth AAC assessments and to investigate and reverse any state practice that denies Medicaid funds for AAC devices. CMS also should work with other federal and state insurers, state insurance commissioners to assure that public and private plans have AAC coverage policies and practices that meet the requirements of the Affordable Care Act and ADA as well as other federal and state laws.

8. Promote equitable access to AAC more broadly.

Despite great advances in technology, education, law, and other fields, many people with significant speech-related disabilities continue to be denied access to robust, language-based AAC strategies, tools, and supports necessary to effectively communicate with others. Students of color, English learners, and those from lower income families face even greater barriers to accessing effective AAC. Deep-seated, systemic prejudice posits such persons cannot comprehend or produce language, and therefore do not need any tools to communicate more effectively. Such bias results in egregious discrimination and degradation.

Research shows that those who lack access to effective AAC are more likely to experience institutionalization, abuse, lower levels of education, and worse employment and health outcomes. Children and adults with significant communication disabilities who are Black, indigenous, or people of color or whose primary language is not English face additional barriers and discrimination. Over three decades after the enactment of the ADA, it is time to bring these gross injustices to an end. As a nation, we must ensure all people with significant communication disabilities have access to AAC and the opportunities to lead decent lives regardless of race, age, class, disability, gender, language, living situation, sexual identity, socioeconomic status, or other classification.

The Biden-Harris Administration should conduct a comprehensive, whole government effort to identify the causes, effects, and extent of this discrimination as well as the short- and long-term actions that must be taken to combat it by creating greater equality of opportunity for people with significant communication disabilities. We strongly recommend the Domestic Policy Council be charged with leading this review in consultation with the Departments of Justice, Education, HHS, other federal agencies, people with significant communication disabilities, their families, and other stakeholders



and that the review’s findings and recommendations be made available to the public and begin to be implemented within the first year of the Administration.

9. Improve and expand data gathering and analysis efforts, and encourage data-driven decision making.

The National Academies of Sciences reports that data on individuals with significant communication disabilities are limited and disjointed and are rarely gathered, analyzed, or used to shape policies and programs that purportedly are designed to serve this high support-need population. How effective are the billions in federal dollars devoted to these programs in terms of ensuring improved education, communication, health, employment, and quality of life? Similarly, characteristic data on this population’s socio-economic status as well as the barriers and discrimination they endure in every sphere of American life is also terribly lacking. In fact, no reliable statistical survey or administrative data exist at the national or state level on the socio-economic characteristics, quality of life, or the unmet needs of this population. When people go uncounted, their needs, rights, abilities, and aspirations are ignored.

Given the known and unknown impacts the pandemic has had on people with significant communication disabilities, it is vital that the Biden-Harris Administration close these gaps in data, knowledge, and policy-effectiveness now. In its review on the need to eliminate discrimination and advance equality of opportunity for such individuals, the Domestic Policy Council should recommend steps to close these gaps.

Over the past year, COVID19, the struggle for racial equity, and threats to our democracy have shown us once again that, as Dr. King wrote, “The ultimate tragedy is not the oppression and cruelty by the bad people but the silence over that by the good people.” We call on President-elect Biden, Vice President-elect Harris, and the new Congress to join with us and provide leadership to end the oppression of silence that is ever present in the everyday lives of millions of marginalized children and adults with significant communication disabilities.

Questions may be directed to CommunicationFIRST’s Policy Director, Bob Williams, at bwilliams@communicationfirst.org, or Executive Director, Tauna Szymanski, at tszymanski@communicationfirst.org. Thank you for your commitment to people with expressive communication disabilities.

CommunicationFIRST

ACCSES

Alliance Against Seclusion and Restraint



American Association on Health and Disability
American Association of People with Disabilities
American Physical Therapy Association
Assistive Technology Industry Association (ATIA)
Assistive Technology Law Center
Association of University Centers on Disabilities (AUCD)
Autism and Communication Center
Autism National Committee
Autism Society of America
Autistic Self Advocacy Network
Autistic Women & Nonbinary Network
Bazelon Center for Mental Health Law
Brain Injury Association of America
Center for Public Representation
Council of Parent Attorneys and Advocates
Disability Justice League
Disability Rights Education & Defense Fund
Disability Voices United
Easterseals
Fund for Community Reparations for Autistic People of Color's Interdependence,
Survival, & Empowerment
HIGH IMPACT Mission-based Consulting & Training
Justice in Aging
Lakeshore Foundation
Little Lobbyists
Moms of Black and Brown Children
National Association of State Directors of Developmental Disabilities Services
National Center for Learning Disabilities
National Council on Independent Living



National Disability Rights Network

National Down Syndrome Congress

National Health Law Program

National Joint Committee for the Communication Needs of Persons with Severe
Disabilities (NJC)

NeuroClastic

Reach

State of Education

TASH

The Advocacy Institute

The Alliance for Citizen Directed Supports

The Arc of the United States

The Aurelia Foundation-Creative Steps Adult Program

The Partnership for Inclusive Disaster Strategies

Therapist Neurodiversity Collective

Union for Reform Judaism

United Cerebral Palsy

United States Society for Augmentative and Alternative Communication

World Institute on Disability