CommunicationFIRST
Because communication is a human right.

OMB Request for Information on Advancing Equity and Support for Underserved Communities (link)

July 6, 2021

Ms. Sharon Block
Acting Administrator
Office of Information and Regulatory Affairs
Office of Management and Budget
Executive Office of the President
Washington, DC 20503

Submitted via: www.regulations.gov

RE: Request for Information for Advancing Equity and Support for Underserved Communities, 85 Fed. Reg. 24,029 (May 5, 2021), Docket No. 2021-0005

Dear Ms. Block,

CommunicationFIRST is pleased to respond to the White House Office of Management and Budget's (OMB) recent Request for Information (RFI) on advancing equity and support for underserved communities, published at 85 Fed. Reg. 24,029 (May 5, 2021).

CommunicationFIRST also joins and endorses the comments submitted today by the Education Task Force of the Consortium on Citizens with Disabilities.

Introduction

CommunicationFIRST is the nation's only nonprofit organization focused on protecting the rights and advancing the interests of the estimated 5 million people of all ages in the United States who cannot rely on speech to be heard and understood due to disability or other condition. Launched in 2019, CommunicationFIRST is led by and for people with expressive communication disabilities. We seek to advance our mission by educating and engaging the public, advocating for policy and practice change, and working within the legal system to protect rights and advance change.

CommunicationFIRST's population of children and adults who rely on various forms of augmentative and alternative communication (AAC) to be understood includes some of the most historically marginalized, excluded, isolated, vulnerable, and underserved people in the United States. Over the past two years, we have prioritized our work on some of the most pressing inequities and issues facing our community. Among other advocacy efforts, we have:

(a) filed a systemic lawsuit against one of the largest school districts in the United States for its discriminatory and harmful overuse of restraint and seclusion practices against students with disabilities[1];

(b) filed and successfully settled two administrative complaints with the Office for Civil Rights at the US Department of Health and Human Services on behalf of patients with communication disabilities who were denied in-person supports necessary to access health care during the COVID-19 pandemic[2];

(c) worked to reintroduce the federal Access to Free Speech for All Act to establish a federally-funded National Resource Center on Augmentative and Alternative Communication to increase access to AAC for those who need it;

(d) created a crowd-funded viral short film called LISTEN[3] to raise awareness in response to the movie *Music*'s harmful portrayal of a nonspeaking autistic person subjected to prone and supine restraints;

(e) educated families on the rights of students with communication support needs to receive in-home supports and other reasonable accommodations necessary to access virtual instruction during COVID-19[4];

(f) issued the Communication Equity Call to Action, incorporated here by reference and enclosed as Attachment A, signed by nearly 50 organizations, calling on the Biden-Harris Administration to take nine key steps to protect people who cannot rely on speech to be understood[5];

(g) led a project funded by the WITH Foundation to improve health care setting communication and increase informed consent for patients with intellectual or developmental disabilities who rely on AAC;

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[1] https://communicationfirst.org/communicationfirst-joins-federal-lawsuit-against-illegal-restraint-and-seclusion/

[2] https://communicationfirst.org/significant-victory-for-patients-with-disabilities-in-response-to-joint-communicationfirst-complaint-on-hospital-no-visitor-policies/ and https://communicationfirst.org/communicationfirst-joins-complaint-against-medstar-for-violating-communication-rights-of-patient/

[3] https://communicationfirst.org/LISTEN/

[4] https://communicationfirst.org/students-know-your-virtual-access-rights/

[5] https://communicationfirst.org/communication-equity-call-to-action/

(h) petitioned the Federal Communications Commission to add accessible text and video-calling options to the National Suicide Lifeline[6];

(i) created a COVID-19 Communication Rights Toolkit for patients[7]; and more.

Regardless of why a person may not be able to rely on speech to be understood, everyone in our community routinely faces discrimination in the form of low expectations, denial of opportunity, and denial of access to reasonable services and accommodations that could reduce or eliminate communication barriers. Because people often mistakenly assume that people who lack intelligible *speech* also are incapable of understanding and using *language*, the vast majority of our population is never even given access to robust language-based communication tools and supports that are necessary for appropriate educational and employment opportunities—and for fundamental agency, autonomy, and self-determination.

These comments respond to three of the five question areas posed in OMB's RFI:

1. Equity Assessments and Strategies. Approaches and methods for holistic and program- or policy-specific assessments of equity for public sector entities, including but not limited to the development of public policy strategies that advance equity and the use of data to inform equitable public policy strategies.

2. Barrier and Burden Reduction. Approaches and methods for assessing and remedying barriers, burden, and inequities in public service delivery and access.

5. Stakeholder and Community Engagement. Approaches and methods for accessible and meaningful agency engagement with underserved communities.

Area 1: Equity Assessments and Strategies

> *"How might agencies collect data and build evidence in appropriate and protected ways to reflect underserved individuals and communities and support greater attention to equity in future policymaking?"*

Recommendation: CommunicationFIRST recommends that OMB, in conjunction with the Domestic Policy Council (DPC) and relevant federal agencies, develop a plan to begin to regularly and systematically collect demographic and characteristic data and statistics on the millions of people in the United States

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[6] https://communicationfirst.org/communicationfirst-petitions-fcc-to-add-text-option-for-suicide-lifeline/

[7] https://communicationfirst.org/covid-19/

who cannot rely on speech to be understood. Failing to accurately track our population and its unique, unmet needs sends the clear message that those who most struggle to have a voice in our nation do not have to be heard or even counted. Whether intentionally or not, this inaction further marginalizes an already insular class of people, rendering us more invisible and powerless.

> <u>Explanation:</u> Despite being among the most marginalized, isolated, segregated, vulnerable, and underserved populations in the United States, and despite the federal government's collecting of data on people with the other two main types of communication disabilities—hearing and vision—there is shockingly little data about people who cannot rely on speech to be understood. The National Academies of Sciences has previously reported that data on individuals with significant communication disabilities are limited.[8] It is difficult to design and implement effective policies for a population without information on their diversity, commonalities, and unmet needs. How effective are the billions in federal dollars devoted to programs purporting to serve this population?
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> Data on our population's socio-economic status as well as the barriers and discrimination we endure in every sphere of American life are also lacking. How many are given access to effective communication tools and supports? How many are given the supports and accommodations we may need to get a job and become taxpayers? How many are given the opportunity to live in the community with meaningful supports? How many are given the tools and supports we need to vote, or even to make decisions about our daily lives? How many are subject to guardianships? Where do we live? Are there racial, socioeconomic, and linguistic factors that make it more likely that someone will be born with or acquire a significant speech disability? Do these intersectional factors impact the likelihood that we will receive access to robust communication tools and supports? **When people go uncounted, their needs, rights, abilities, and aspirations are ignored.** Especially given the 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.

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[8] National Academies of Sciences, Engineering, and Medicine; Health and Medicine Division; Board on Health Care Services; 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. *The Promise of Assistive Technology to Enhance Activity and Work Participation*. Washington (DC): National Academies Press (US); 2017, May 9. 6, *Augmentative and Alternative Communication and Voice Products and Technologies*, at: https://www.ncbi.nlm.nih.gov/books/NBK453284/

Recommendation: CommunicationFIRST recommends that this effort begin with creating a uniform federal classification term like "individual with significant expressive communication disability" or "individual with significant speech-related disability."

Recommendation: The National Institute on Disability, Independent Living and Rehabilitation Research (NIDILRR) and other federal agencies should work together to issue a joint RFI on what relevant demographic data exist already at federal, state, and local levels, what is missing, and how existing data collection efforts can be modified to fill this significant data gap. Specific attention should be paid to understanding how racial, ethnic, and linguistic characteristics make the inequities experienced by those with significant expressive communication disabilities worse.

> Explanation: Since the 1990s, the federal government has regularly collected data on non-institutionalized persons with six types of disabilities that result in difficulty in (1) hearing, (2) vision, (3) cognitive activities, (4) mobility, (5) self-care, and (6) independent living. People with speech-related disabilities are not counted separately. Some do not fit into any of these categories, and some fit into several of them simultaneously, leaving us effectively invisible.
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> Large population surveys have also gathered data on the extent to which individuals with one of these six disability types rely on certain assistive devices such as wheelchairs, canes, and hearing aids. Such data first was collected in the National Health Interview Survey (NHIS) of 1990, and showed that 13 million individuals required one or multiple assistive devices to carry out essential tasks. The 1990 NHIS also found only 38,000 individuals living in the community reported using some type of AAC and that 55 percent were age 65 and older.[9] Despite the enormous gains that have been made in AAC and related fields since 1990, this marked the first and only time a federal survey asked a question on the use of AAC specifically. In 1994-1995, the CDC together with other federal agencies, carried out a major supplement to the NHIS to generate a comprehensive profile of the characteristics of children and adults with disabilities in the country. The disability supplement reported that an estimated 7.4 million people with disabilities reported using one or more of 29 different types of assistive devices to compensate for hearing, limb loss/limb

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[9] LaPlante, M.P., Hendershot, G.E., & Moss, A.J. (1992), Assistive Technology Devices and Home Accessibility Features: Prevalence, Payment, Need, and. Trends. CDC National Center for Health Statistics. Advance Data from Vital and Health Statistics No. 217.

difference, mobility, or sight disabilities. It paid scant attention, however, to persons needing AAC.[10]

In 2013, researchers estimated that about 1.3 percent of the total population, or 4 million people in the United States, "cannot rely on their natural speech to meet their daily communication needs,"[11] and that "the prevalence and complexity of communication disorders increase with age."[12] The National Academies of Science, other federal agencies, and professional associations have cited the 2013 estimate as the only, and therefore the most authoritative, one available. Other studies suggest that the numbers of children, working-age persons, and older adults with significant speech disabilities likely will continue to increase due to several factors, including:

- The changing demographic makeup of the country in terms of age, longevity, race, ethnicity, primary language, education, economic mobility, digital innovation, connectivity, and other SES factors;
- The rising incidence of autism;
- Advances in medicine resulting in improved survival coupled with lifelong disability;
- Extended lifespans of individuals with communication disability; and
- Improved AAC technology that better meets the needs of people with physical and cognitive disabilities.[13]

The pandemic and racial disparities are threatening the health and lives of our community in an unparalleled manner. Individuals who require AAC are often needlessly illiterate, institutionalized, isolated, immunocompromised, kept incommunicado, and wrongly regarded as lacking in the capacity, need,

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[10] CDC National Center for Health Statistics, National Health Interview Survey Supplement on Disability – Number of Persons Using Assistive Technology Devices, 1994, Table 1a; *see also* J.N. Russell et al., Trends and Differential Use of Assistive Technology Devices: United States, 1994; CDC National Center for Health Statistics (November 1997). Advance Data No. 292.

[11] Beukelman, D.R. & Mirenda P. (2013). *Augmentative and alternative communication: Supporting children and adults with complex communication needs*, at 4. 4th ed. Baltimore, MD: Paul H. Brookes Publishing Co.

[12] Flaubert, J.L., Spicer, C.M., Jette, A.M., eds., *The Promise of Assistive Technology to Enhance Activity and Work Participation*. Washington (DC): National Academies Press (US); 2017, May 9. 6, *Augmentative and Alternative Communication and Voice Products and Technologies*, at: https://www.ncbi.nlm.nih.gov/books/NBK453284/ (citing Yorkston K.M., Bourgeois, M.S., Baylor, C.R.. *Communication and Aging. Physical Medicine and Rehabilitation Clinics of North America*. 2010a;21(2): 309–319, at https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3074568/).

[13] Flaubert, J.L., Spicer, C.M., Jette, A.M., eds., *The Promise of Assistive Technology to Enhance Activity and Work Participation*. Washington (DC): National Academies Press (US); 2017, May 9. 6, *Augmentative and Alternative Communication and Voice Products and Technologies*, at https://www.ncbi.nlm.nih.gov/books/NBK453284/ (internal citations omitted).

or right to communicate and thus control our lives.[14] This discrimination is endemic in health care contexts; see, for example, **here**, **here**, and **here**. Furthermore, due to entrenched racism and health disparities, Black Americans and other people of color are more likely to experience a 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**.

Improving the quality and comprehensiveness of data on such individuals will not erase or salve these egregious injustices in the daily lives of such persons. But, until we as a nation conscientiously count children, working-age persons, and older adults with significant expressive disabilities, and begin to fashion and implement data and evidence-based federal policies and programs that address their needs, abilities, fears, and hopes, their lives and our democracy will be made the worse for it. When people are not counted in a valid manner they never truly count.

For a data strategy to be effective in providing an accurate and comprehensive profile of those that either currently use or need access to an array of AAC tools to effectively communicate throughout their lives, these nuances need to be acknowledged and addressed to the greatest extent feasible.

Area 2: Barrier and Burden Reduction

"Members of underserved communities may experience a variety of external factors that may disproportionately affect their access to information about programs or program eligibility [and] applying for benefits, ... These barriers may include, but are not limited to: … limited proficiency in English, disability, low literacy, income or other resource constraints, stigma in accessing public programs, and limited access to technology. Other barriers are internal to the administration of programs. While certain program rules may ensure that benefits are awarded to eligible individuals or are otherwise required by law, others are not necessary for ensuring benefits are

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[14] See Kleinert, J., Holman, A., McSheehan, M., Kearns, J. (2010). *The Importance of Developing Communication Competence. Synthesis Report #1.* Lexington, KY: University of Kentucky National Alternate Assessment Center. USDOE OSEP #H3244040001; NAS, *Promise of Assistive Technology*, Ch. 4; CommunicationFIRST, National Survey Reveals Students with Communication Disabilities Are Being Denied Safe Access to Education (Jan. 4, 2021); CommunicationFIRST, Are AAC Users at Greater Risk of Dying from COVID? (Updated) (Dec. 20, 2020).

awarded to eligible individuals and may be remedied via administrative or regulatory changes."

Recommendation: **The Administration should stop encouraging the further marginalization of our community that occurs when the government endorses or requires us to be branded with low IQ scores from biased assessment tools before we can gain access to services and supports.**

> Explanation: Despite abundant evidence that they are inaccurate and inappropriate for people who cannot rely on speech to be understood and have other motor disabilities, standardized IQ-type assessments are used to segregate, isolate, and deny opportunities to not just school-age people but also many adults who require public funding to survive. The federal government's encouragement in guidance and regulations of the use of these assessments sanctions widespread prejudices and stereotypes that frequently make those that use or need AAC easy marks for bullying, abuse, assault, and lifetimes of dehumanization.
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> In the Communication Equity Call to Action that CommunicationFIRST and 47 other organizations submitted to the Administration this past January, we specifically encouraged the Department of Education to review the extent to which IQ tests and similar cognitive assessments are inappropriately used with students with motor and speech disabilities, and to determine appropriate short- and long-term actions to prevent and reverse their use and effects. Currently, intellectual disability (whether perceived or actual) is inappropriately and regularly used as a basis to deny students access to robust, language-based AAC.
>
> There is also a large body of research on the biased, discriminatory impacts that standardized IQ assessments have—independent of disability status—on Black, indigenous, people of color, linguistic, and other minority individuals and communities; see, for example, **here** and **here**. Special attention should be paid to whether these assessments are used to disproportionately marginalize racial, ethnic, and linguistic minority populations of people with significant expressive communication disabilities. 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.

Recommendation: **Specific, early steps that OMB and the DPC can take to address the inequities caused by the inappropriate use of IQ assessments include the following:**

- Announce a nationwide ban on the use of federal funding to conduct or otherwise use standardized IQ-type assessments with students who need but lack effective AAC;
- Provide guidance that such tests should not be used on someone with a speech or motor disability unless they are able to communicate effectively with AAC tools and supports and to use AAC to take such tests;
- Provide funding for 3 to 5 states that agree to ban the use of standardized IQ-type assessments for students who need but lack effective AAC and to pilot measures to increase the deployment of robust, language-based AAC to such students; and
- Direct the Department of Education to provide added funding, guidance, and technical assistance to achieve these purposes.

Recommendation: **OMB and the DPC, in conjunction with the Department of Justice, should conduct a comprehensive, whole government effort to identify the causes, effects, and extent of discrimination against people with significant expressive communication disabilities, as well as the short- and long-term actions that can be taken to combat it by creating greater equality of opportunity for such individuals. Guidance, training, technical assistance, and other measures should be developed and implemented to clarify, stress, and emphasize to all covered entities what Section 504 of the Rehabilitation Act and the Americans with Disabilities Act anti-discrimination, integration, and effective communication mandates mean specifically for children, working age, and older adults with significant expressive communication disabilities.**

It is critical that:

- The review identifies barriers to and strategies for ensuring all people with significant expressive 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 review is carried out in consultation with the Departments of Education, Health and Human Services, other federal agencies, people with significant communication disabilities, their families, and other stakeholders; and
- The review's findings and recommendations are made available to the public and begin to be implemented as soon as possible.

Area 5. Stakeholder and Community Engagement

Persons with significant expressive communication disabilities, our families, and our allies must play a lead role in designing, delivering, evaluating and improving policies and practices affecting access to, the financing of, and the effective use of AAC. It is imperative to operationalize and apply this principle at the individual and the systemic levels. Consumer control and self-determination are bedrock principles and deeply embedded throughout federal disability civil rights and related statutes, policies, programs, and practices.

These same principles and expectations must drive all federal efforts concerning AAC. The voices and views of such persons have gone unheard and unheeded generation after generation. We can and must break this cycle by insisting that our voices matter and must be heard. Early steps in doing so could include the following actions:

<u>Recommendation:</u> **Issue an RFI, host town hall sessions, or just listen to persons who rely on AAC talk about their lives, what's working, what's not, their dreams and fears as well as their insights and recommendations on how the federal government and others can best enable their success.**

<u>Recommendation:</u> **Fund a National Center on AAC and Empowerment directed and majority staffed by individuals who rely on AAC and are diverse in respect to race, disability, language, culture, and other characteristics to:**

- Provide information, training, peer education and support principally to individuals with significant expressive communication disabilities and other stakeholders when appropriate; and
- Offer technical assistance to federal agencies and others on assuring their policies and practices are responsive to the needs, abilities, and rights of all who use or lack access to AAC.

<u>Recommendation:</u> **Use individuals who rely on AAC as paid consultants, grant reviewers, and in other capacities and lead roles in designing, delivering,**

evaluation and improving policies and practices affecting access to, the financing of and the effective use of AAC.

<u>Recommendation:</u> Take explicit steps to involve young people and adults who require AAC as active participants in community, national, and international service efforts in order to thwart the bias that we have little to say and far less to contribute.

<u>Recommendation:</u> Take explicit steps to recruit, hire, retain, and promote qualified individuals who use AAC throughout every level of the federal government as well as by federal contractors and grantees.

<u>Recommendation:</u> Fund writers, film makers, story tellers, and other artists using AAC to tell their stories, their truth, and the stories and truths of many others who require and use or lack access to robust language based AAC.

* * *

It is said that individuals and communities are most at risk of experiencing overwhelming bias, discrimination, and oppression when they, others, and government regard them as lacking a voice, a positive identity, and the human agency to improve their lives. This must not continue to be the fate of millions who require AAC. Civic engagement of all forms is a powerful antidote for thwarting these forces and to enhance individuals' hearts and minds, their health, self efficacy, and sense of belonging. The steps outlined here are vital for beginning this process.

Thank you once again for the opportunity to provide information on this important topic. We can be reached at bwilliams@communicationfirst.org and tszymanski@communicationfirst.org for further information.

Sincerely,

Bob Williams Policy Director	Tauna Szymanski Executive Director & Legal Director

ATTACHMENT: Communication Equity Call to Action (Jan. 14, 2021)

ATTACHMENT

CommunicationFIRST
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