



AAC Counts Project Public Webinar

February 23, 2023

Transcript

Webinar slides ([PPT](#)) ([PDF](#))

Tauna Szymanski: Welcome. My name is Tauna Szymanski and I am the Executive Director and Legal Director of CommunicationFIRST, the nation's only civil rights organization led by and for people in the United States who, due to disability or other condition, cannot rely on speech to be heard and understood.

My pronouns are she and her, and I'm a white woman with long, wavy brown hair. I'm wearing glasses and I have a wonky left eye. I'm thrilled to welcome everyone to today's webinar, which will share the results of a one-year project that is designed to lay the groundwork to improve the data and statistics that are available about the millions of people in the United States with significant speech related disabilities who must rely on various forms of augmentative and alternative communication, or AAC, to be understood.

We are recording today's webinar and it will be available on the [AAC Counts project website](#) next week along with a transcript. Before we get started, I will point out the accessibility features of today's webinar.

First, we are providing interpretation in American Sign Language and we are also providing real-time captioning. You can turn on the captions in your Zoom window by clicking on the CC button at the bottom of your screen.

To minimize distractions, we ask that you put any questions or comments you may have in the Q&A box, which you can access by clicking on the Q&A button at the bottom of your screen. Finally, you are able to access these slides on the [AAC Counts website](#), and I'm going to ask Erika to paste that website link in the chat now, if anyone needs them to access this presentation live.

Later on, we'll be posting an executive summary, a plain language version of the report, and other project materials on that site. We're still putting the finishing touches on some of these materials and everything will be posted by early next week.

Over the next hour or so, our goals are, first, to introduce you to the wonderful team that worked on this project, some of whom are not actual data wonks, but *are* passionate about people who need and use augmentative and alternative communication, or AAC, and recognize that to make



any significant progress toward achieving equity for this historically marginalized group, we need actual data first. We will then provide a bit more background about why we decided to do this project.

We will then provide a summary of our key findings and then a list of our main recommendations for policy makers. Finally, we will conclude with next steps, and we will have time to take questions and comments at the end. You can enter your questions in the Q&A box at any time.

My colleague, CommunicationFIRST Policy Associate Ren Koloni, will present most of the Project's findings today, and we will also hear briefly from some of the members of our Thought Leader Panel and from our partners at DREDF.

Before I turn it over to Ren, I will take just a minute to introduce the people who made this project a reality. Over the past year, everyone at CommunicationFIRST—all five of our employees—spent many hours working on this project, but my colleague and co-founder, Policy Director Bob Williams, and Ren Koloni really deserve the vast majority of the credit for getting the project to where it is today. Erika Prado and Tony Alexander also have spent numerous hours on this.

We unfortunately could not convince Bob to spend his birthday presenting the report today and, really, who can blame him, but we know he will continue to dedicate himself with his usual passion to this project for months to come.

We also have to thank our partners at the Disability Rights Education and Defense Fund, or DREDF, who immediately recognized the importance of this project when we approached them about it.

Susan Henderson, Mary Lou Breslin, and Sylvia Yee have been instrumental in helping us secure grant funding and in identifying important California sources of data and policy reform opportunities. Alyssa Hillary Zisk, a part-time AAC user and recent PhD in neuroscience was an independent consultant during the first half of the project, and we thank them for helping to get the project off the ground and conducting the initial research.

And last but not least, Stephen Kaye, a very prominent disability statistics expert, affiliated with the University of California, San Francisco, gently and generously volunteered his time and expertise to ensure that the other project team members who did *not* have formal training in demographics didn't muck things up too much.

Thank you, Steve.



We were extremely fortunate to have been able to recruit an amazing and diverse panel of Thought Leaders to help guide and inform this project. The panel had a mix of AAC users, disability data experts and experts in different aspects of our population. For people who cannot see the slides, I will quickly read their names and affiliations.

Alixé Bonardi from HSRI and former coordinator of the National Core Indicators Project, which we will mention a bit later. Yoosun Chung from George Mason University, who focuses on the use of assistive technology and special education and independent living. Melissa Crisp-Cooper, a California-based health policy consultant and member of CommunicationFIRST's Board of Directors. Charles Ellis from the University of Florida, and an expert on people with acquired speech loss and aphasia. Tawara Goode of the Georgetown University National Center for Cultural Competence and a longtime ally of our community.

Clarissa Kripke, of the University of California, San Francisco, and a member of CommunicationFIRST's Board of Directors. Saili Kulkarni, from San Jose State University, and an expert in multiply marginalized students with disabilities. Charlie Lakin, the former director of National Institute on Disability, Independent Living, and Rehabilitation Research.

Gloria Soto from San Francisco State University, and an expert on multicultural AAC users and AAC and language development. Hari Srinivasan, a PhD student in neuroscience at Vanderbilt University. Bonnielin Swenor, the founder and director of the Johns Hopkins Disability Health Research Center. And Sahar Takshi from the Equity and Elder Justice Teams at Justice in Aging.

To learn more about any of these experts, you can access their bios on the AAC Counts webpage, and we thank all of them for their tremendous contributions to this project. Several of them had conflicts today, but sent in comments to be read aloud, which we will do later in the program.

Now I'm going to invite Mary Lou Breslin from DREDF to say a few words. Mary Lou, are you there? There you are. Can you unmute and turn on your camera?

Mary Lou Breslin: There we go. Hi.

Tauna Szymanski: Hi. Welcome!

Mary Lou Breslin: Thank you very much, Tauna, and hi everybody, and thank you for joining us today. My name is Mary Lou Breslin. I'm a senior analyst at the Disability Rights Education and Defense Fund. We're a national law and policy center with offices in the San Francisco area and in Washington, DC.



All of us at DREDF are so pleased to have had the opportunity to partner with CommunicationFIRST on this project. It really, for the first time, aims to lay the foundation for improving the quality and the availability of data about people with significant speech-related disabilities who rely on AAC to be heard and understood.

This collaboration was really natural for us, because several of us at DREDF had been advocating for disability data collection in electronic health records and administrative data for over a decade. So our work perfectly aligned with the work of CommunicationFIRST and the goals of this project. Many of you know very well that those of us working for disability data collection specifically in the healthcare area have a saying, although it certainly applies in general to data collection across the board: **who counts depends on who is counted.**

So, in other words, we can't improve what we can't measure. The groundbreaking AAC Counts report that you'll be hearing about today presents what I believe is really the first comprehensive picture of why we need data, what's missing, and what existing data will tell us. The report also includes comprehensive recommendations for adding questions to population and other surveys, and I have no doubt that this report is going to garner attention from policymakers and lead to needed reforms.

I'd also like to personally thank Bob and Tauna and Ren and the other staff of CommunicationFIRST for their leadership on this project. They've been tenacious advocates and allies, and the final report—it really reflects that commitment. So thank you so much for this partnership. We've enjoyed it, and we think the report is going to have a great impact.

Tauna Szymanski: Thank you so much, Mary Lou. It's been so great working with you and your colleagues on this project.

All right, so how did we get here? When CommunicationFIRST launched in 2019 and we were setting our policy agenda, we had trouble finding data to help us prioritize the long list of issues we knew we needed to tackle.

So right away, it became clear that we needed to change this—that if we were going to be able to successfully advocate for policy change, we would need to be able to point to statistics—basic data—to explain why what we were advocating for was indeed a priority, and should be a priority for policy makers and others as well.

The problem that we encountered is that working on data and statistics is not very exciting to most funders. After a few years of unsuccessfully applying for grants to support this work, we were lucky to find partners in DREDF and in California-based Ability Central, who both



immediately recognized the importance of this initiative, and Ability Central agreed to provide a year of funding for the AAC Counts project.

The project's goals were simple. We started out by researching what had already been collected and analyzing what data already exist. We also spent some time listing out all the information we thought we *should* be able to know about our population, but simply do not and cannot right now due to this absence of data, the type of data that is available for folks with most other kinds of disabilities, but simply has not yet been collected on people who cannot use speech alone to be heard and understood.

And then we aimed to create a list of recommendations for both California state and federal policy makers, as well as researchers and demographers who might be able to begin to move the needle.

We also hope that the resources from this project can be used by people who use and need AAC, their family members, and others who support our community to advocate for improved data collection efforts. In short, the overarching goal of the AAC Counts project was to lay the groundwork to eventually count and more accurately characterize our people.

We need to start somewhere to document, for instance, how educated or uneducated this group of people is, how healthy or unhealthy, how employed or unemployed, and what inequities they face in accessing, not just AAC, but basic services and accommodations that are needed to have equal opportunity to participate as members of society.

Accurate data is essential for effective policymaking, service delivery, and government funding. As Mary Lou noted, we count the things we care about in society. And as my colleague Bob Williams says, **"If you aren't counted, you don't count."**

We are invisible, underserved, and underrepresented.

The AAC Counts project urges policy makers and researchers to begin to count people who cannot rely on speech alone to be heard and understood.

So now with that background and introduction, I'm going to turn things over to my colleague Ren to dive a bit deeper into what we found.

Ren Koloni: Hello. My name is Ren Koloni. I am a Program Associate here at CommunicationFIRST. I am a fat, white, non-binary person with glasses and half-shaved, long, braided brown hair. I use they/them pronouns.



I was fortunate to be able to do a lot of work for this project. As an AAC user myself, I know firsthand of our community's incredible diversity, as well as the significant obstacles we face, but firsthand knowledge is not the same thing as data.

Data is information on a large scale. It helps us see connections that we just can't make out from our perspective as individuals. It helps us find and understand patterns, and it keeps people accountable.

Stories from AAC users are powerful tools, but numbers can tell us with much greater precision how well or how poorly we're doing in protecting some of our nation's most marginalized.

Who might those most marginalized be?

In this report, we've used the phrase "people who need AAC" to talk about anyone with a significant speech disability who needs augmentative and alternative communication, or AAC, to be heard and understood by others. Some of us may use speech some of the time, like myself. Some of us may never use speech. Some of us may be born with these difficulties. Some of us may develop them later in life.

Our disabilities may be motor-based, cognitive, neurological, or a combination. Many of us have multiple diagnoses, but some of us will never have a diagnosis at all.

We are an incredibly diverse group, but we are united in one thing. Each of us needs access to AAC in order to fully participate in our communities.

Tauna Szymanski: This is Tauna speaking. Melissa Crisp-Cooper is one of our Thought Leaders who could not be here today. She sent the following comment to be read aloud:

"Those of us with communication disabilities are often either left out of research and policy decisions, or counted as one homogenous group. We are a complex, multifaceted group with different skills, goals, and needs. Hopefully, this report will highlight our diversity and begin to change how we are represented. Accurate information will allow decision makers to create better policies, fund innovative projects, and truly understand the people in my community."

Yoosun Chung, another member of our Thought Leader Panel, shared the following:

"AAC has opened doors for me that I never thought possible. It has enabled me to teach at a university and actively participate in my academic and social community. Since I began using AAC, it has made a huge difference in my life, and I know that it can do the same for others who are facing similar challenges. That's why I believe that it's so important to advocate for AAC and to make sure that it's available to everyone who needs it. It is important to collect better



demographic data about people who use and need to help us gain a deeper understanding of the needs of individuals with complex communication needs. The AAC Counts project is therefore crucial to advancing the field of AAC.”

Ren?

Ren Koloni: Because no rich national data has ever been gathered on our population, there are so many questions we have yet to answer. How many of us are there in the United States? This should be a simple question, but there is no simple answer. A 2020 estimate puts our population at 5 million, or 1.5% of the American population, but it is likely larger.

We know very little about our demographics, such as gender, race, ethnicity, community language, disability, or socioeconomic status. **Understanding demographics is key to understanding disparities between demographic groups.**

For example, does it take longer for people of color to access AAC than white people? Do people with certain disabilities have an easier time accessing AAC than others?

We know that many of us still do not have access to AAC, even though the cost of speech-generating devices has plummeted over the past decade. Other people have been forced to wait years, even decades to be able to communicate with language. We need to know more about these violations of basic human and disability civil rights.

We need to know more about our experiences in education. The data we *do* have tells a scary story. We found a study that found only 1.1% of nonspeaking students who use AAC are placed in inclusive classrooms for even part of the day. This same study found that only 3% of nonspeaking students who use AAC could understand words they read.

We need integration, literacy, and access to AAC devices to receive an equal education and to be prepared for leaving the school system. How many of us have been denied those things?

We need to know more about employment and poverty. How many of us are fairly employed and making enough money to live well?

And we need to know about a significant part of our population—people who live in institutions, nursing homes, or other congregate settings. Available data suggests that we are the last population to be deinstitutionalized after the *Olmstead* decision, and that few of us living in these settings have access to AAC.

These are some pretty fundamental questions that we really should know the answers to. We know the answers to many of these questions for people with other types of disabilities or



demographic characteristics, but we can't answer them about people who need AAC. This project aims to help change that

Tauna Szymanski: This is Tauna speaking again. And we'd now like to invite a couple of our AAC Counts Thought Leaders who were able to be present today to share any comments they may have. Do we have... It looks like we have Gloria ready. Gloria, are you there? If you could turn on your—there you are! Welcome. So, Gloria Soto is from San Francisco State University.

If you don't mind, Gloria, providing an image description before you start? And, welcome.

Gloria Soto: Thank you, Tauna. Yes. My name is Gloria Soto. I go by she, her. I'm a middle-aged woman of Hispanic origin. That explains the accent. I have brown eyes, brownish skin, I guess. And I'm wearing a gray top.

And I want to thank you, Tauna, for inviting me to participate in this very important project. I was very impressed with the rigor with which this team has conducted this very important study. And for me, I think there are two things that really stuck out, or two main issues I think that I respected. I respected very much the focus on inclusivity of all dimensions of diversity when we talk about users of AAC.

And we realize that the AAC community, the AAC-using community, is incredibly diverse, not only in terms of etiology or conditions for which the need of AAC is there, but also in terms of language backgrounds, ethnic backgrounds. As we were involved in this project, we realized, or at least we saw evidence of what everybody knows, which is that there are glaring and unsustainable inequities in access to AAC and access to quality services. It's not enough, as we saw in the course of the project, to provide someone with an AAC device if there is no supports provided to ensure that the AAC becomes an integral part of this person's communication system.

I think for me as a professor and as a researcher, this project provides very needed evidence for the need of the work that we are doing. I hope that this report really trickles down to agencies, especially federal agencies that establish research and policy priorities. But I think that something also that was very important, and is very important, is that by being counted, we're supporting—not the birth, because the AAC community already exists. Nobody needs to validate it, nobody needs to—it's there, right? But I think this project is going to give a presence to the AAC community that perhaps has not been there before in the same way. And I think that is very exciting as we move forward. So thank you. Thank you again.

Tauna Szymanski: Thank you so much, Gloria.

Charlie Lakin, are you there?



Charlie, if you're there, could you turn on your camera and unmute?

Charlie Lakin: Unmute?

Tauna Szymanski: There, I hear you. I don't see you.

Charlie Lakin: Okay. Start video.

Tauna Szymanski: So Charlie Lakin is the former director of the National Institute on Disability, Independent Living, and Rehabilitation Research, or NIDILRR, and has an affiliation, or did have an affiliation, at the Research and Training Center on Community Living at the Institute on Community Integration, University of Minnesota.

And we weren't sure he was going to be able to show up today because he lives in Minnesota where there's been [*laughter*] like eight feet of snow. So welcome. We're so happy that you made it, Charlie.

Charlie Lakin: Hello, everyone. Charlie, I'm he and him and an older, portly fellow with a blue sweater on.

First, I'd just like to reiterate what Mary Lou said about the importance of CommunicationFIRST and the importance of this project. Really want to thank the people who worked on it, and of course, those who supported it.

I spent my whole career in the area of measurement and there are a lot of truisms. And in the area of measurement, Peter Drucker basically said, "If we don't measure things, we can't improve them." For me, it's more that **if we don't try to measure something, it really shows we don't view it as important.** And our national datasets are just totally inadequate in addressing communication impairments within our population.

We've just really undervalued communication as a gateway to all those goals we profess for people with disabilities. We talk about people having greater independence. We talk about them being included. We talk about higher rates of employment and increased self-determination. We talk about people being able to advocate for themselves and, and you ask, which of these is not measurably enhanced by improved levels of communication?

It just seems that communication is such a basic foundation to all those goals, to inclusion, to independence, to self-determination, to self-advocacy. To really participate in our society, you need to be able to communicate with others, and so the promotion of that is so, so important.



You know, obviously, millions of Americans of all ages experience a variety of physical, medical, intellectual, mental limitations that affect their ability to communicate. And I think a major difficulty we have had in identifying the needs of people who can't communicate very well or very understandably through spoken words, are that there are members of so many distinct categorical classifications.

And so within those groupings, we tend to know a little bit about our populations, but we have a very limited understanding of communication impairment as a general problem that permeates all those groups. And so I really appreciate the steps recommended in this report to address this complex reality.

I think they'll communi—they will contribute to improved understanding of the prevalence of communication impairments, and also to increased attention to communication impairment in policy, in programs, in technology development, and in other interventions.

So again, I'm really—I'm really excited about this project being an important step in improving how well we understand and can help people who cannot communicate clearly through spoken words.

Tauna Szymanski: Thank you so much, Charlie. So glad you still have power and heat as well. [Laughter] And we were so thankful to have your guidance and participation in the project.

I think at least one other Thought Leader is with us today, and can say a few words. Clarissa Kripke, who is associated with the University of California, San Francisco, is a medical doctor and is also on our Board of Directors. Clarissa, welcome.

Clarissa Kripke: Hi. Thank you. I am so grateful for the work of CommunicationFIRST because as a physician who serves adults with developmental disabilities, many of whom do not use speech to communicate, I understand full well that communication is the foundation of patient care.

Eighty percent of making an accurate diagnosis is based on the history, and nobody else knows someone's internal experiences and what they're feeling inside their body except for the person. So other people who are supporting them and other people who are observers are not able to know what's going on with the patient.

And we are so much more efficient and so much more accurate in our diagnoses and in keeping people healthy, which ultimately saves money for the healthcare system and improves quality of life.

So, in order to make sure that people have access to communication in healthcare settings, we absolutely need this project, we need the data, and then we need to use it to make sure that people



have the ability to tell their own stories to their doctors about their symptoms so that people can be healthy. I appreciate it. Thank you.

Tauna Szymanski: Thank you so much, Clarissa, and thanks to all of our Thought Leaders again for your participation and sending in comments. We really appreciate it.

Okay. I'm gonna turn things back over to Ren to talk a little bit more about some of the details of what we found with the report. All right.

Ren Koloni: How can we gather data? One way that has been used in many studies over the years is diagnosis. But there are issues with that approach, so many that it is no longer used to collect national disability data.

This graphic shows available estimates of the number of people with a certain condition who are likely to need AAC, but it raises more questions than it answers.

For example, many people with childhood apraxia of speech are also, or will later be, diagnosed with autism. We don't know how many. And many AAC users have multiple disabilities, so sorting out who gets counted where is a difficult task.

There's also the fact that we just don't have prevalence data for many conditions, including ones that likely number in the millions of people who need AAC, such as dementia and Alzheimer's or traumatic brain injury.

Estimates based off of diagnosis and prevalence data just won't work.

Other surveys have tried using age-related proxy indicators. They might survey a particular set of grades in a public school system, or they might survey all Social Security beneficiaries. But significant speech disability can and does occur at any point in our lives. Surveying just one age group misses out on big parts of our population.

We could look at who has AAC devices or gets AAC services, but so many AAC users, like myself, use homemade methods, or never get professional services. Again, this strategy misses out on so many people, especially those of us who continue to be denied AAC.

The only way to do this right—and it must be done right—is to ask functional limitation questions in large population surveys. This is the gold standard of disability data these days, and for good reason.



Tauna Szymanski: This is Tauna speaking again, and I'm going to share another comment from one of our Thought Leaders who could not be here today. Bonnie Swenor, a disability data equity expert from Johns Hopkins University, commented,

“Data are a powerful tool for creating societal change. But the absence of data on marginalized populations and groups erases opportunities to address the injustices they face. This important project not only focuses on closing data gaps for people who use AAC, but doing so in ways that gives power back to this community. I am grateful for the opportunity to work with and learn from this team.”

Ren?

Ren Koloni: So, which national sources already gather data on us? Not many.

The CDC's National Health Interview Survey, or NHIS, started asking a question about us in 2019. But it conflates difficulty being understood with difficulty understanding. These disabilities are totally different, and it makes the question functionally useless for gathering data on communication disabilities.

The NHIS also gave us a supplement on voice, swallowing, speech, and language disabilities. It was first done in 2012, and again in 2022, though fewer questions were asked. It's the largest source of data we have on our population to date, but it didn't ask about AAC access, and excluded institutionalized people.

The most robust data we have, apart from the NHIS, is from all the way back in 1995 when the NHIS conducted its survey on disability, the NHIS-D.

No other surveys that ask about us ask about AAC access. This includes the CDC's National Health and Nutrition Examination Survey, the HRSA's National Survey of Children's Health, the NIH's National Health and Aging Trend Study, the SSA's National Beneficiary Survey, and CMS's Minimum Data Set.

One survey does ask about “usual method of communication”—the National Core Indicators – Intellectual and Developmental Disability, or NCI-IDD. This survey only looks at people with I/DD, but it gathers rich data on many facets of our well-being, such as feelings of safety, ability to make friends, and ability to make choices about our lives.

This is information we urgently need. **The NCI-IDD isn't perfect, but it is a great start.**

The NCI-IDD has uncovered some concerning issues. In a 2014 report, nonspeaking respondents, who make up about a quarter of all respondents to the NCI-IDD, reported



significantly worse outcomes than their speaking peers. That included worse overall health, more anxiety about their safety, less community engagement, and significantly less ability to make choices about their lives.

More data is urgently needed to better understand exactly why and how this is happening, and to guide policy measures to alleviate these outcomes.

How can we improve government surveys? We need to start by including people who need AAC.

Some of the most important information for policy and disability civil rights comes from the American Community Survey, or ACS. Although the international standard from the Washington Group asks about seven functional limitations, one being communication, the ACS only asks about six. People who need AAC are left out of ACS data, and as a result, expressive communication needs are completely absent in the process of distributing more than 675 billion dollars in funding.

We need to gain the trust of people who need AAC by making sure these surveys are accessible to them. Surveys also need to talk to us directly, avoiding proxies wherever possible. If we need more help answering survey questions, we should turn first to a system called “assisted response,” used with great success in 1994 with the NHIS-D.

And we need to include those who live in group settings, including institutions, nursing homes, jails, and prison. Out of all the surveys that currently ask about us, only the Minimum Data Set, a survey specifically for nursing home residents, and the NCI-IDD gather information about people who need AAC in congregate settings.

Tauna Szymanski: Thank you, Ren. This is Tauna again, and I’m going to read one final comment from an AAC Counts Thought Leader, Alixe Bonardi, who is affiliated with the NCI-IDD work that Ren just mentioned. Alixe writes,

“Thank you to the leadership at CommunicationFIRST and to the collected group of passionate leaders who have leaned in on this issue and have laid out a strong case for making sure that people who do not use words to communicate are counted and heard. **Yes, it takes extra work to be sure that people who are often overlooked are accurately reflected in national health and other quality data sets and data systems. That’s work that needs to be done to be sure all means all.**”

Ren, back to you.



Ren Koloni: Our recommendations emphasize continuity, comparability, and equity. These factors increase the reliability and usefulness of data and assure that those who have been ignored by data and policy will begin and continue to be meaningfully included.

Data continuity requires ongoing funding for agencies like the U.S. Census Bureau, federal and state disability agencies, and other researchers. It's not enough to do just one supplemental survey. We need long-term data to understand how the needs of people who require AAC change over time, especially since most of us have significant speech disabilities for our entire lives.

To assure data comparability, federal surveys should strongly consider using the internationally-used Washington Group functional limitations. **Unfortunately, the reason the question on the NHIS is useless for us is that the Washington Group's original question is useless too. It needs to be modified before it can be used. We suggest something like, "Do you have difficulty speaking or using speech to be understood by others?"**

To ensure equity, collect data directly from us, include people in congregate settings, and leverage multiple sources to gather as much cross-cutting demographic information as possible. Data on justice, education, health, benefits, and more could be at our fingertips.

Some solutions are especially close at hand. States, including California, can implement check boxes on IEPs to indicate the presence of speech delays and whether a student needs and has AAC.

The state of California also has two surveys well-suited to gathering data on Californians who need AAC. The California Health Interview Survey, or CHIS, reaches over 20,000 Californians and asks about many health and disability issues, but not speech disability. The California Client Development Evaluation, or CDER, gathers information on many Californians with I/DD, but currently there is no way to respond to the survey as or for someone who uses language-based AAC. This can change.

We've outlined many more recommendations in the full version of our report.

Tauna Szymanski: Thank you so much, Ren. So, onto next steps.

We are working feverishly to finalize all the pre-publication materials, including the final report that was just mentioned, as well as shorter pieces, including an executive summary, plain language version, several one-pagers on specific topics, as well as some infographics.

These will all be posted on the AAC Counts webpage by the end of the month, which is early next week. When everything is posted, we'll be sure to email everyone who registered for today's



webinar to let you know. And at that point, we welcome any feedback and suggestions for improvements on these materials before we produce and disseminate more professionally formatted and accessible versions of all the materials.

We also plan to share our results and recommendations with state and federal US-level policy makers and researchers, and look forward to meeting with anyone who is interested in advancing this work. Better data on our population will help to improve equity and access, and this is work we are passionate about making sure gets done. So we do hope that you will join us in this important work going forward.

And now we are happy to address any questions or comments that have been posted in the Q&A box.

So the first question is from Amy Goldman, who asks, “Do you include people who are deaf?” And I can, unless Ren, do you want to take that, or do you want me to take it? Okay, go ahead.

Ren Koloni: In short, we include people who are deaf if they consider themselves to have a speech disability. Our focus is on people whose primary speech disability is not about their hearing or ASL as their primary language, but that does not necessarily totally exclude deaf people.

Tauna Szymanski: Another question from Nicola Sowah. She asks, “Do you have plans to extend this study globally?” So I can answer that, if that’s all right, Ren.

It was challenging enough to convince people to fund us to do one country. But I will say that a lot of the findings from our report and our recommendations, I think, translate, or can translate well to, to other countries and settings, and in fact, some of the findings and recommendations we have are actually based on some work that was done outside the U.S.

So there will be—there are sections of the report that include some references to international and other country data—disability statistic data collection work.

So at this time, CommunicationFIRST has no plans to extend this project outside the U.S. In fact, as an organization, we are focused on the U.S. in general anyway, so. But we’d be happy to work with any other organization who’s working on this internationally to see if we can compare notes and support that effort.

There’s a question from Kathleen Diviak, which is, “How can family members best share the results of your report and advocate for their AAC user?”



So I can take that one, if that's all right. I think we do—some of the things that we'll be posting on the page include shorter versions of the report, not so technical—using not-so-technical language and some key takeaways.

This is really, this effort is really about, sort of, systemic change, looking very broadly at the large population of people who need AAC in the U.S., the vast majority of whom we believe do not have access to robust, language-based augmentative and alternative communication, in order to help improve policies that may affect folks that are part of this population.

So this won't be something that can benefit an individual AAC user per se. But it's really aimed to sort of change the landscape for the whole community.

But that said, we do encourage individual members of our community to join us in advocating with your members of Congress or other state and federal policy makers, if you are interested in doing so, to help improve data collection and policies surrounding those efforts.

So I hope that answers that question.

Amy Goldman has a comment: "It seems like your focus is on what some refer to as aided versus unaided communication and excludes multimodal communicators. Difficult and important work."

So Ren has a response for this. So go ahead, Ren.

Ren Koloni: As we detail further in the report, though we are talking about all people who cannot rely on speech to be understood, when we talk about AAC, our focus is on robust, language-based AAC. CommunicationFIRST believes that communication equity means valuing, but not stopping at, what some call unaided AAC.

Language-based AAC matters because we need ways to use words and syntax in order to communicate effectively about anything we want, whenever we want, under any circumstances. Hence our language choices.

Tauna Szymanski: Right. And I think there's a related question from an anonymous attendee: "Is the target population people who need or use AAC? Or people, for example, with sensory or movement disabilities? Or does it include everyone who doesn't use speech, including those who don't use it for cognitive reasons? How do you distinguish those populations given that people with sensory movement disabilities are often presumed to have cognitive disability?"

Ren, do you wanna follow up?

Ren Koloni: I do not use speech for cognitive reasons. So it is about everyone.



Tauna Szymanski: Are there any other questions or comments?

Ren Koloni: I'm typing.

Tauna Szymanski: Go ahead.

Ren Koloni: In terms of distinguishing the populations, part of what we argue is that we do not necessarily need to. We need to gather data on people who need AAC as a group. Part of gathering that data can be asking about why they need AAC, but we know that these reasons are complicated and asking about them in detail will take dedicated research.

Tauna Szymanski: Yeah, I can just add to that. I mean, it is an extremely—as was mentioned several times today, it's an extremely diverse group of people. The one thing, I mean, the reason why CommunicationFIRST itself was structured to include this broad, cross-disability population, including people who are born with speech-related disabilities and people who acquire them, is really twofold.

So first is that, regardless of why someone can't rely on their own speech to be understood, every single person in this situation experiences discrimination and prejudice and low, just, you know, discriminatory attitudes and everything. So that is universal across reasons, or any age of onset, for a speech-related disability.

And the second reason, which is less relevant to this particular project, but is relevant to our civil rights work, is that the laws on communication rights in the United States are actually fairly robust, and they apply regardless of why someone may have a communication disability or how long they've had it.

So to us it just, it really did make sense to make this a cross-disability effort, both as an organization in our work as a whole, but also specifically in terms of data. And if you think, so you know, the ACS, not the "AX" [*as Ren's AAC device initially, and incorrectly, pronounced it!*] but the ACS, the American Community Survey, they add two of the six questions.

One of them is, do you have a hearing disability or difficulty hearing? And another one is, do you have difficulty seeing or do you have a vision disability? And those are communication, right? Vision and hearing are both other types of communication.

And people within those two populations also have very, very diverse experiences, right? Very different reasons for why they may have acquired a vision or a hearing disability, and also age of onset, including, you know, people who are born without hearing completely or acquired it later, and then different degrees of it.



So there's really no difference in our population in terms of diversity of, you know, etiology (to use, you know, the medical term), or like how they got it and also when they got it and how significant, or how high their support needs are in terms of being able to communicate and what kind of supports they might need. There isn't universal—there aren't universal communication supports, really, in either of the other categories as well.

So, Ren, do you wanna handle the questions from Rina, or...?

So, I can read it aloud while you're typing: "What do you envision as the best survey tool and best survey body to collect the needed data? I imagine it will be a combination. Maybe NIH surveys, improved... a virtual portal, data contributed by service providers, schools, question mark." And then later, Rina says, "For context, I'm a late diagnosed autistic. I'm in a Master's program in data science, and I want to do my capstone project on something that uses data on disabled populations and or in service to those populations. I'm not an AAC user, but I know those who are."

Ren Koloni: We are looking for a robust body of data, and that means multiple sources of data. We strongly believe that the ACS should include a question on speech disability because it would gather so much important information for policy development. But, improved NHIS surveys and the addition of significant speech, disability, and AAC use to a number of other federal data sources, including the CDC's BRFSS, IDEA-mandated data collection under the Department of Education, and surveys from the Bureau of Justice Statistics, just to name a few.

We have many more recommendations in the full report and encourage you to read more when they are released next week.

Tauna Szymanski: All right. Are there any other questions? I'm looking at the time.

All right.

Oh, so Kathleen follows up on her earlier comment: "Following back on my comment on how family members can be useful. Is there a way that family members can communicate to these agencies about this?"

It's likely we will—I mean, we *will* be continuing this project, even though our grant funding has concluded.

As probably is evident, we're very passionate about this work, and we will continue it in whatever form we can in the years to come. I would imagine—I do imagine that we will be doing what we can to set up meetings with policy makers around the country and holding additional webinars like this



to try to get the word out about the importance of this work and to include some suggestions for specific agencies.

And the final report, you'll see, does break out a lot of our recommendations to specific agencies. So we will almost certainly have specific suggestions for our membership to support this work and to continue engaging on it. So that's a great question. Thank you so much.

So... All right, wonderful. So I am going to wrap things up, I think, at this point.

We thank you so much for attending today and for all of your interest in ensuring people who can't rely on speech to be heard and understood are finally counted. Please do sign up, if you're not receiving our newsletters now, you can sign up at <https://communicationfirst.org> to receive that, and that's the place where we'll have future updates about AAC Counts-related news and resources and potential engagement opportunities if we have future webinars or meetings and suggestions for how to push forward this work.

So we look forward to collaborating with many of you on the next steps to ensure we truly count all the people and things we care about in society. So thank you so much.