
AAC COUNTS

The Urgent Need for Better Data About People with Significant Speech Disabilities



Access

- American Sign Language
- Real-time captioning (CART)
- Q&A box
- Slides, plain language version, and other project materials:
<https://communicationfirst.org/aac-counts/>

Goals Today

- Project partners
- Background
- Summary of key findings
- Policy recommendations
- Next steps
- Questions and comments

Project Team

- Bob Williams, CommunicationFIRST Policy Director
- Tauna Szymanski, CommunicationFIRST Executive Director
- Tony Alexander, CommunicationFIRST Program Associate
- Ren Koloni, CommunicationFIRST Program Associate
- Erika Prado, CommunicationFIRST Program Associate
- Mary Lou Breslin, DREDF Senior Policy Advisor
- Susan Henderson, DREDF Executive Director
- Sylvia Yee, DREDF Senior Staff Attorney
- Alyssa Hillary Zisk, Independent consultant
- Stephen Kaye, Professor at the Institute for Health & Aging and the Department of Social and Behavioral Sciences, University of California, San Francisco

AAC Counts Thought Leader Panel

- Alixe Bonardi, MS, Human Services Research Institute
- Yoosun Chung, PhD, George Mason University
- Melissa Crisp-Cooper, California-based health policy consultant
- Charles Ellis, PhD, University of Florida
- Tawara Goode, MA, Georgetown University National Center for Cultural Competence
- Clarissa Kripke, MD, University of California, San Francisco
- Saili Kulkarni, PhD, San Jose State University
- Charlie Lakin, PhD, former Director of NIDILRR
- Gloria Soto, PhD, San Francisco State University
- Hari Srinivasan, Vanderbilt University doctoral student in neuroscience
- Bonnielin Swenor, MPH, PhD, The Johns Hopkins Disability Health Research Center
- Sahar Takshi, JD, Justice in Aging

Disability Rights Education and Defense Fund (DREDF) Comments

Mary Lou Breslin, DREDF Co-Founder and
Senior Policy Advisor



Why are we here?

When CommunicationFIRST launched in 2019, we had trouble finding data to support our advocacy and policy priorities.

We knew we needed to change this.

In 2022, **Ability Central**, based in California, provided us with funding for the AAC Counts Project, which CommunicationFIRST and the Disability Rights Education & Defense Fund (DREDF) have worked on together.



About AAC Counts

Project goals

- Research and summarize data that *is* available
- Summarize what we don't know
- Make recommendations for policymakers

We count the things we care about in society. We must begin to count people who cannot rely on speech alone to be heard and understood.

Who is our target audience?

Policymakers | Researchers | People who need AAC | Family members |
Anyone invested in our community

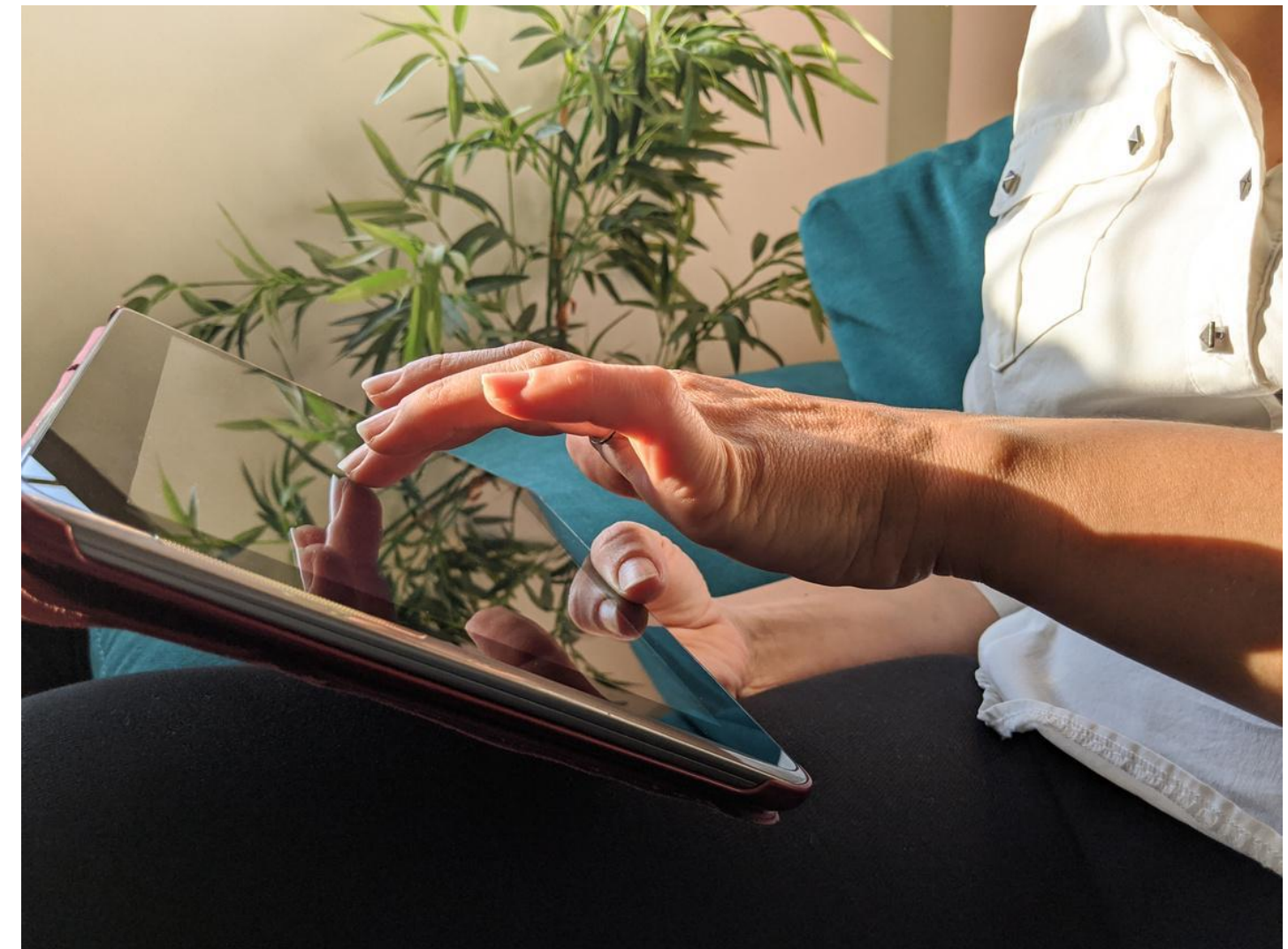
The Importance of Data

Data is critical for tracking and understanding our community's unmet needs, along with what policies are needed to bridge gaps in access, equity, and services



Who are we talking about?

- People with significant speech disabilities who need augmentative and alternative communication (AAC)
 - People who cannot rely on speech alone to be heard and understood
- Some of us use speech some of the time and some of us never use speech
- Our speech disabilities may be motor-based, cognitive, and/or neurological



**Melissa
Crisp-Cooper
Independent health
policy consultant,
AAC Counts Thought
Leader Panel**

Those of us with communication disabilities are often either left out of research and policy decisions, or counted as one homogeneous 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, Ph.D. George Mason University, AAC Counts Thought Leader Panel

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 AAC 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.

- 01.** How many of us are there in the United States?
- 02.** Are there disparities between groups of AAC users?
- 03.** Who has access to AAC and who doesn't? How long does it take people on average to get access to AAC?
- 04.** How many of us graduate from school without having a way to communicate effectively with language?
- 05.** How many AAC users have jobs?
- 06.** How many residents of group homes, nursing homes, or other long-term care facilities don't have a way to communicate with language?

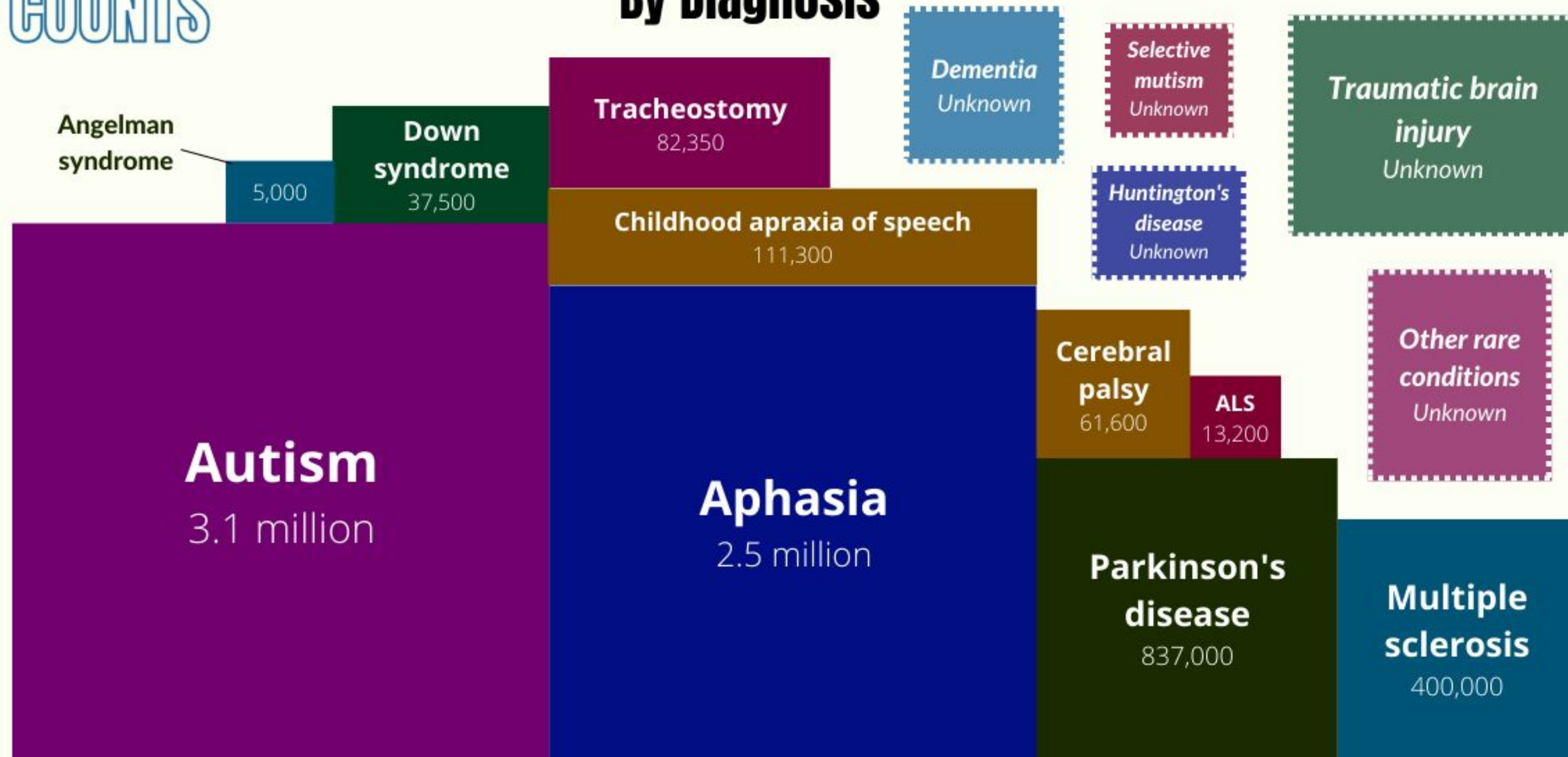
Some Key Questions

Comments from AAC Counts Project Thought Leaders

Sources of Data

- Diagnostic (not used anymore in broad disability surveys)

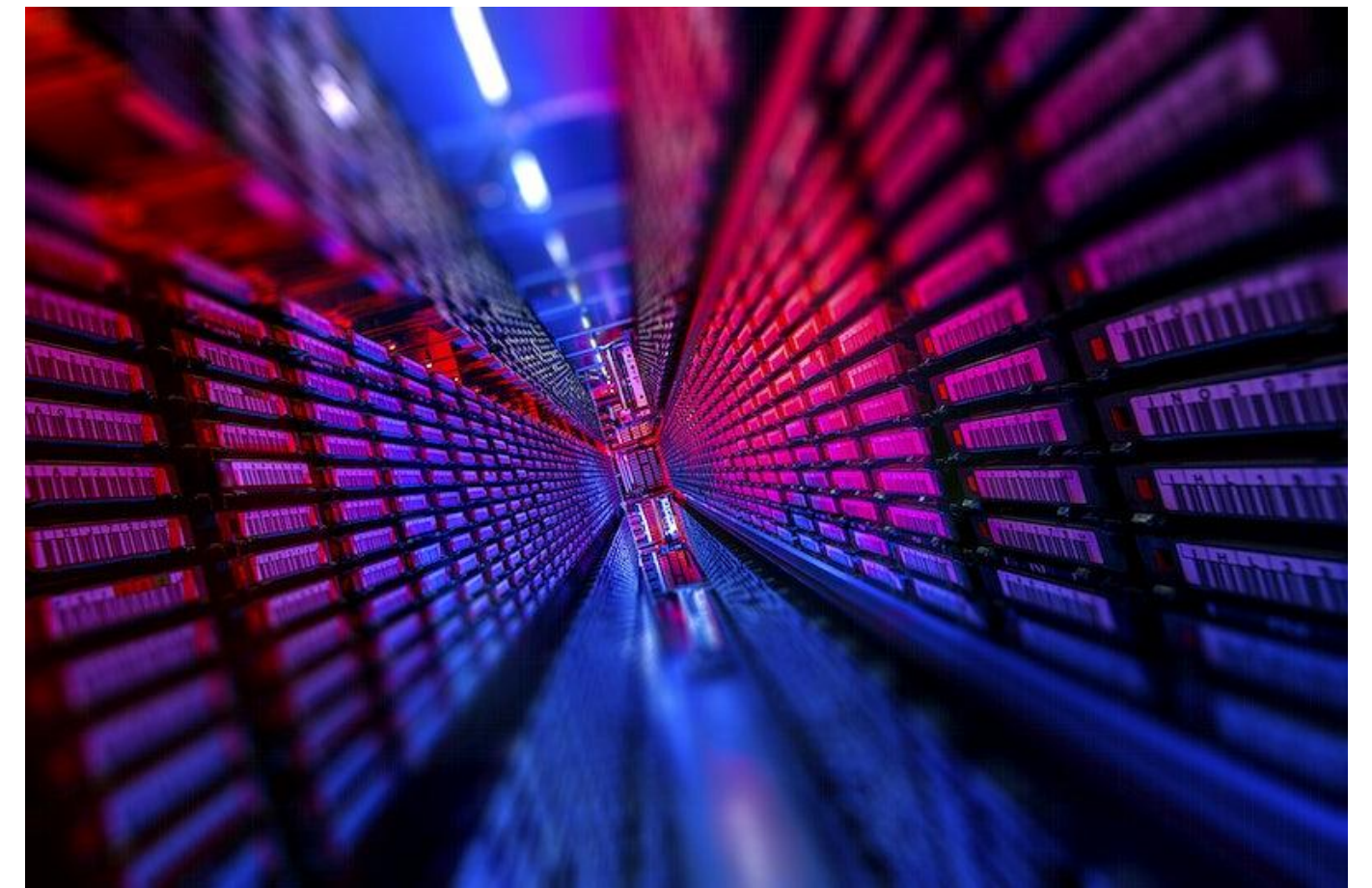
Estimates of People in the U.S. Who Need AAC By Diagnosis



This image graphically represents the estimated numbers of people in the United States who need AAC by diagnostic category, using current available population data for each category, multiplied by the estimated prevalence of significant speech disabilities in each category. Because the population count and prevalence calculation methods used in each category are not consistent or reliable, the numbers reflected in this graphic should not be assumed to be an accurate estimate of AAC need in the United States. The size of each square is not an exact representation of the numbers. Not all relevant diagnoses are included, due to lack of available data, and since not all people who need AAC have a diagnosis. CommunicationFIRST (c) 2023.

Sources of Data

- Diagnostic (not used anymore in broad disability surveys)
- Age-related proxy indicators (school age, Social Security)
- Who has devices or gets services?
- Functional limitation questions in surveys (non-medical model)



**Bonnielin
Swenor,
Ph.D., MPH
The Johns Hopkins
University,
AAC Counts Thought
Leader Panel**

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.

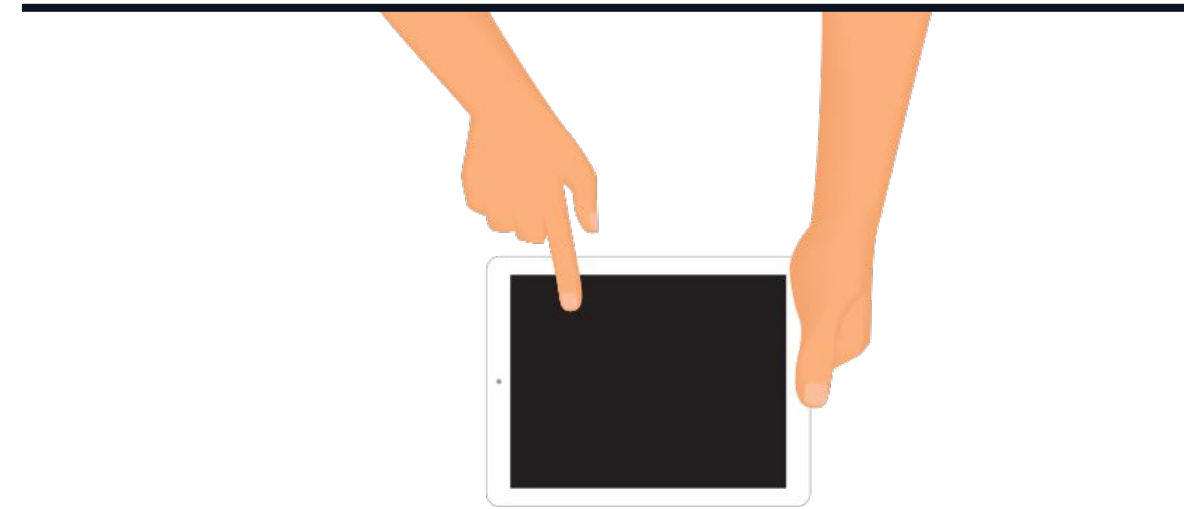
I am grateful for the opportunity to work with and learn from this team.





- 25% of respondents were nonspeaking
- Compared to speaking respondents, nonspeaking respondents reported:
 - Worse overall health
 - More anxiety about their safety
 - Less community engagement
 - Much, much less ability to make choices about their lives

Improving Government Surveys



Who is Surveyed

- Most disability data sources don't collect data on speech-related disabilities and conditions
- Who gets excluded from surveys? Who gets to answer?

Build Trust

- Ask AAC users how to improve survey administration
- Creating accessible surveys will help improve trust among people who need AAC

Include Group Settings

- Some surveys exclude those in group settings
- American Community Survey (ACS) variables don't break down nursing homes, jails, prisons, other institutions

**Alixé Bonardi,
MS
Human Services
Research Institute,
AAC Counts Thought
Leader Panel**

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 datasets and data systems. That's work that needs to be done to be sure all means all.

Key Recommendations

1

CONTINUITY

Increase funding for research on people with significant speech disabilities. Include us in longitudinal data banks like the CDC's DHDS.

2

COMPARABILITY

Modify and use the functional domains adopted by the Washington Group:
“Do you have difficulty speaking or using speech to be understood by others?”

3

EQUITY

Collect data directly from disabled people, using assisted response when necessary.
Include people in institutions.
Gather all kinds of data.

Next Steps

- Pre-publication materials to be posted on AAC Counts webpage by February 28
- Receive feedback
- Produce professionally formatted, accessible versions
- Share results and recommendations with state and federal (US) policymakers and researchers
- Ongoing public engagement and work! Join us!

Comments? Questions?

Email info@communicationfirst.org

Webpage <https://communicationfirst.org/aac-counts/>