

AAC COUNTS

AAC Counts II: What Existing Data Can and Cannot Tell Us About People with Significant Speech Disabilities

AAC Counts - Part 2: What Existing Data Can and Cannot Tell Us About People with Significant Speech Disabilities

Table of Contents

Preface ([jump](#))

- A. The Population of Focus
- B. About This Project
- C. Language Use
- D. Accessibility

I. The Population ([jump](#))

- A. Population Estimates
- B. Demographic Characteristics

II. AAC Access ([jump](#))

- A. Denials and Delays
- B. Professional Issues

III. Pressing Issues ([jump](#))

- A. Demographic Disparities
- B. Education and Literacy
- C. Guardianships
- D. Employment, Socioeconomic Status, and Benefits
- E. Healthcare
- F. Violence and Harm
- G. Social Support Systems

Appendices (available on AAC Counts webpage)

- A. References
- B. List of Data Needs
- C. Table of Existing Prevalence Data by Disability or Condition
- D. Key National Sources of Demographic, Disability, and Health Data
- E. Acknowledgements



Preface

A. THE POPULATION OF FOCUS

An estimated five million people in the United States experience disabilities or other conditions that impact their ability to rely on speech alone to be heard and understood. Some are born with limited speech or no ability to speak, and some experience speech limitations at later stages of life. People who cannot rely on speech alone to be heard and understood experience widespread bias and discrimination from not being seen, heard, or counted, regardless of the cause or age of onset of their disability or condition.

Augmentative and alternative communication, or AAC, is any tool, method, or support used by a person with a speech disability who cannot rely on speech alone to be heard and understood by others. People may use AAC all the time, most of the time, or episodically. In this report, unless otherwise specified, we use AAC to refer to language-based AAC.

Many people have speech disabilities, but not all need AAC in order to participate fully in the community. Although the recommendations in this report will likely benefit all people with speech-related disabilities if implemented, this report focuses on the children and adults who currently use AAC, and those who need AAC but have not yet been able to access it. To describe this latter group, we use the phrase “people who need AAC.” Communication is not a luxury, but an immutable part of life and a fundamental right.

Anyone who cannot rely on spoken language alone to be heard and understood, regardless of age, cognitive ability, or community language, requires AAC to express themselves, interact with others, and to be a meaningful part of their communities.

People who need AAC may have a variety of congenital, developmental, or acquired disabilities, including co-occurring cognitive, physical, neurological, and psychological conditions. It is important to acknowledge that historically and to this day people who need AAC are disproportionately and incorrectly identified as having significant cognitive disabilities. However, cognitive disabilities are not predictors of significant speech disability, nor is significant speech disability indicative of cognitive disability.

Needing AAC is about much more than diagnosis. Some people who use or need AAC do not and will never have a diagnosis. Ultimately, this population is characterized by a shared need for AAC, not by a list of diagnoses.



Because this project's funder, Ability Central, is located in California, the AAC Counts project pays particular attention to existing data and policy recommendations relevant to the state of California. However, the research findings and recommendations presented in this report are relevant to researchers and policymakers nationally, and potentially internationally.

B. ABOUT THIS PROJECT

Unlike people with hearing and vision disabilities, people with significant speech disabilities are not systematically counted by either California or the federal government. Failing to track this unique population's size, demographics, and living conditions makes it difficult for policymakers to identify and appropriately address this marginalized group's unmet needs and challenges. Until people who need AAC are counted, they and their unmet needs will remain out of sight and out of mind, and thus unaddressed by policymakers. Without reliable data, it is very difficult to advocate effectively for the policy change needed to advance the interests of this historically marginalized community.

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The AAC Counts project aims to lay the foundation for improving the quality and availability of state and national statistics about people in the United States with significant speech disabilities who need AAC to be heard and understood.

The information gathered over the course of this project is organized into two reports. This report, "The Urgent Need for Better Data," examines current federal and state-level data collection on people who need AAC. The second, "What Existing Data Can and Cannot Tell Us," assesses how the questions identified by this report as vital for future policy efforts are, or are not, answered by existing research. Taken together, these reports reveal both data inequities and inequity in the everyday experience of people who need AAC. The third report contains policy recommendations and paths forward to address these issues.

C. LANGUAGE USE

All people, regardless of access to spoken language, use multiple modes of communication (such as facial expressions, gestures, sounds, or writing). In a society that privileges spoken words, however, people without access to speech need AAC in order to be heard and understood. Although AAC traditionally has been considered to include communication modes such as facial



expressions and gestures, true communication equity means ensuring everyone has access to robust, language-based AAC. While everyone can use some form of non-speech communication, such as pointing or eye gaze, not everyone has access to AAC that enables the full range of communication to which all people have the right.

We acknowledge and regret having to reference several studies that use inaccurate, damaging, and offensive terminology. It was only some twenty years ago that the term “mental retardation,” used to label people with developmental disabilities and to mark them as incompetent and inhuman, was used diagnostically. The National Health Interview Survey, a widely-used federal source of health data, continued to use this term until 2011, when it shifted to “intellectual disability, also known as mental retardation.” Although the term is now considered a slur and has been excised from most nonprofit and clinical contexts in the United States, the recency of such violence embedded in the language referring to part of our population is no small matter.

The use of harmful and ableist language, of course, has not ended. CommunicationFIRST, DREDF, and many others, including some AAC users, view the use of terms like “nonverbal” to describe anyone who requires AAC as inaccurate, damaging, and offensive, yet this terminology is still widely used by professionals and the general public. We and others who need AAC also object to the terms “special needs” and “complex communication needs.” Given how few sources of relevant data are available, this report cannot avoid referencing surveys and papers that use dehumanizing language; it is important to acknowledge its presence and the damage it has done.

People who use AAC to be heard and understood were asked in the spring of 2022 about the language and terminology they prefer to be used to describe themselves and their disabilities (Zisk & Konyn, [2022](#)). Although more research is needed in this area, we have used the preliminary results of this survey to guide language used in this report.

We also note that, due to the cross-disability nature of this population, as well as the inherent diversity of the disabled community in general, there is no consensus among people who use AAC regarding the use of person-first versus identity-first language. To show respect to all members of the community, this report makes reference to both “people with disabilities” and “disabled people.”

We hope that this acknowledgement, as well as the purposeful choice of language used in this report, will serve as a reminder that achieving a more just society rests largely on how we choose to perceive and describe each other.



D. ACCESSIBILITY

We are deeply committed to maximizing communication access in the work we do. This includes increasing access to people who may benefit from a plain language version of this report. One is available on the AAC Counts website (<https://communicationfirst.org/aac-counts/>), along with an Executive Summary and visual representations of key pieces of the report.

All visual images used in this report and on the AAC Counts webpage contain alt-text, and efforts have been made to ensure that this report meets web accessibility standards.

If you have an accessibility concern or would like to request a copy of this report in a different format, please email info@communicationfirst.org.

I. The Population

A. Population Estimates

National estimates of the number of Americans unable to rely on speech alone to be heard and understood have varied enormously. In [1952](#), the American Speech-Language-Hearing Association (ASHA) Midcentury Committee for Children and Youth estimated that 7.5 million Americans had some kind of “speech defect,” including “functional articulatory [defects], stuttering, voice [problems], cleft palate speech, cerebral palsy speech, retarded speech development, and impaired hearing (with speech defect).” In 1983, National Health Interview Survey (NHIS) data was used to estimate that 1.1% of the nation, or 2.2 million people at the time, had a speech or language impairment (Fein, 1983).¹ Yet direct evaluation greatly increased rates of speech or language impairment, pushing the actual estimate to 4.2% of the population, about 9.9 million people (Fein, 1983). The NHIS’s Voice, Language, and Speech Supplement in 2012 found a prevalence of 16.5 million, or 7%, although this figure included those with swallowing difficulties as well (Hoffman et al., [2014](#)).

However, these estimates were inclusive of *all* speech or language disabilities, regardless of severity or need for AAC. A 1987 ASHA publication estimated that approximately 2 million Americans in the U.S. “are unable to speak or demonstrate severe communication impairments” (ASHA, 1991); this figure of 0.8% was used for many years to estimate the number of AAC users in America (e.g., Huer, [1999](#)).

Recently, more widely-cited estimates of people needing AAC in the United States have included 4 million in 2013, or 1.2% (Beukelman & Mirenda, 2013), and 5 million in 2020, or 1.5% (Beukelman & Light, 2020), both of which are closely aligned with the 1.5% prevalence estimated in the 2001 Canadian Participation and Activity Limitation Survey (Cossette & Duclos, [2003](#)). Assuming these more recent estimates are correct, and assuming uniform geographical distribution, **approximately 5 million people in the United States, including 588,000 Californians, currently**

¹ The NHIS stopped collecting annual data on people with speech impairments in 1996 (National Center for Health Statistics, [2022b](#)).



need AAC (using 2021 population estimates).² However, as discussed below, **the existing U.S. estimates appear to lack the rigor and comprehensiveness that are necessary to truly achieve data equity.** Even if these estimates are inaccurate, they are included here as a reference point for this section’s discussion.

a. Federal sources

National Health Interview Survey (NHIS) Supplement on Voice, Swallowing, Speech, and Language Problems

- Centers for Disease Control and Prevention (CDC)
- National Institutes of Health (NIH)
- National Institute on Deafness and Other Communication Disorders (NIDCD)
- Federal - Every 10 years - Institutionalized people excluded

A 2012 supplement to the National Health Interview Survey (NHIS), funded by the National Institutes of Health (NIH)’s National Institute on Deafness and Other Communication Disorders (NIDCD), collected data on voice, swallowing, speech, and language problems, particularly those lasting over a week (National Center for Health Statistics, [2012a](#); [2012b](#)). Using this data, Hoffman et al. ([2014](#)) found that 7% of the adult U.S. population (16.5 million adults) had a voice, swallowing, speech, or language problem lasting over a week in the year prior to the survey.

Also using this data, the NIDCD reports that 5% of children between the ages of 3 and 17 had “speech problems,” and 3.3% experienced a “language disorder” over the last year. In addition to breaking down prevalence by age range (Ages 3-6: 11.0%; Ages 7-10: 9.3%; and Ages 11-17: 4.9%), the data contains likelihood of receiving interventions (speech conditions: 67.6%; language conditions: 66.8%; and voice conditions: 22.8%) (NIDCD, [2016](#)).

Survey on Income and Program Participation (SIPP)’s 2014 SSA Supplement

- U.S. Census Bureau
- Federal - 2014 only - Institutionalized people excluded

² However, based on prevalence estimates for a number of conditions that lead to AAC need and using the proportion of each population estimated to have significant speech difficulties, this number is at least 7,173,320 people in the U.S., or about 2.16% (see **Appendix C** for more details). Although the epidemiological approach is not wholly accurate, the sheer size of this number—even lacking the numbers of populations for which we have no data on prevalence or likelihood of speech difficulty— suggests that the estimates in use are likely undercounts.



The **Survey on Income and Program Participation (SIPP)** previously included a speech disability-related question in topical modules in 2008 and in the 2014 SSA Supplement (U.S. Census Bureau, [2017](#)). In a 2014 supplement to the SIPP, children under the age of 18 were considered disabled if they met at least one criterion, including “difficulty having their speech understood.” Despite the fact that this was not a criterion used to identify disabled adults, adults taking the survey were nonetheless asked about difficulty having their speech understood. Approximately 4.9 million (2.1%) adult respondents reported having difficulty with their speech being understood in the language spoken in their home (of which 13.1% could not at all be understood); 1.4 million (27.4%) of those respondents also had serious hearing difficulties (Taylor, [2018](#)).

National Survey of Children’s Health (NSCH)

- Health Resources and Services Administration (HRSA)
- Maternal and Child Health Bureau (MCHB)
- Federal - Annual - Excludes institutionalized children

In 2020, 5.8% of parents participating in the **National Survey of Children’s Health (NSCH)**, reported that their child had a speech or language disorder, putting the estimate of children with a speech or language disorder in the U.S. at over 3.5 million (The Child & Adolescent Health Measurement Initiative, [n.d.a](#)). This is not, however, an estimate of how many children need AAC to be heard and understood by others.

Minimum Data Set (MDS)

- Centers for Medicare & Medicaid Services (CMS)
- U.S. Department of Health and Human Services (HHS)
- Federal - Quarterly - Nursing home residents

The CMS’s **Minimum Data Set (MDS)** is a collection of data on residents of nursing homes and includes two questions of relevance to this population. In 2021, a question on “speech clarity” indicated that 86.6% of residents have “clear speech,” 9.9% have “unclear speech,” and 3.4% have “no speech.” Another question is asked about residents’ ability to make their needs and wants understood, via “verbal and non-verbal expression”: 66.4% are “understood,” 18.3% are “usually understood,” 9.3% are “sometimes understood,” and 5.8% are “rarely/never understood.” The MDS does not report on assistive device use or access to AAC (CMS, [n.d.b](#)).

Analysis reveals that significant speech disabilities are a major contributing factor to long-stay nursing home residence for younger residents. 93.1% of residents aged 0-19 have an expressive



communication impairment, combined to 39.1% of residents across age groups (Ne’eman et al., [2022](#)).³

b. State sources

National Core Indicators—Intellectual and Developmental Disabilities (NCI-IDD)

- National Association of State Directors of Developmental Disabilities Services (NASDDDS)
- Human Services Research Institute (HSRI)
- Participating states - Annual - Includes institutionalized people

Some states participating in the NCI-IDD elect to include a question about “preferred means of communication,”⁴ including spoken language, gestures, sign language, and communication devices. In the most recently available report covering the 2020-2021 cycle, two-thirds of California respondents were reported to “prefer” spoken communication, one-third were reported to “prefer” gestures or body language, and less than 1% were reported to “prefer” sign language, finger-spelling, a communication device, or to have an unknown “preference.” In addition, 8% were reported to need additional communication technology services (National Core Indicators, [2022](#)). However, some respondents who report using spoken communication may do so not because it is the most effective form of communication for them, but because they lack access to AAC, and have no choice but to use speech that few understand.

In 2014, an NCI report found that nearly one quarter of all respondents to the NCI-IDD Adult Consumer Survey “do not communicate verbally” (Hiersteiner et al., 2014).

Residential Information Systems Project (RISP)

- Institute on Community Integration at the University of Minnesota
- State I/DD agencies
- Participating states - Longitudinal - Institutionalized people with I/DD

In 2016, RISP reported that 52% of people with IDD living in public residential facilities “could not express their needs verbally” (Residential Information Systems Project, [2016](#); [n.d.](#)).

³ Compared to 43.1% among residents aged 20-34, 34.3% among residents aged 35-49, 31.4% among residents aged 50-64, and 40.3% among residents aged 65+ (Ne’eman et al., [2022](#)).

⁴ The word “preferred” is not appropriate for describing the type of communication used by individuals. Even if an individual has some access to speech, AAC is not a “preference” but a necessary way to access the fundamental human right of communication. To recognize that AAC is not a choice or preference, researchers should instead use the phrase “means of communication.”

c. *International sources*

Canada's Participation and Activity Limitation Survey (PALS)

- Statistics Canada
- Canadian - Replaced by the Canadian Survey on Disability (CSD), no longer conducted

The 2006 PALS found that 44.8% of children with one or more disabilities reported a communication disability, making it the third most prevalent disability among this age cohort (Statistics Canada, 2006).

Australia's Survey of Disability, Ageing, and Carers (SDAC)

- Australia Bureau of Statistics (ABS)
- Australian - Annual

The 2018 SDAC revealed that out of the 4.4 million Australians living with a disability, 3.9 million had a disability affecting core activities, including communication, mobility, or self-care disability. This data cannot be disaggregated, so it is unclear how many have a communication disability, or how many of those with a communication disability have a significant speech disability specifically. The SDAC did report that 3.1% of children had a sensory or speech disability, though this was again not possible to disaggregate, and severity was not reported (Australian Bureau of Statistics, [2019](#)).

Autistic people are a population of priority for the SDAC, which reported that 42.3% needed assistance with communication, 23.8% needed assistance with communication at least daily, and 34.3% needed more help with communication than they were currently receiving (Australian Bureau of Statistics, [2019](#)).

B. Demographic Characteristics

Age

Many conditions contribute to AAC need later in life, such as amyotrophic lateral sclerosis (ALS), Alzheimer's, dementia, Parkinson's, and aphasia as a result of stroke (Beukelman et al., [2007](#)). Furthermore, the longer an individual lives, the more likely they are to experience a disabling event that may contribute to AAC need, such as traumatic injury or illness such as cancer. Many studies

have focused on school-age children, but more research is needed on older adults because the prevalence of speech disability increases with age (Hirdes, Ellis-Hale, & Hirdes, [1993](#)).

Previous research investigating the prevalence of speech disabilities primarily focused on certain age groups, inevitably skewing data. Additionally, most prevalence data on this population is outdated (e.g., Boyle et al., [2011](#); Raghavan et al., [2018](#)). Recent research has attempted to provide new estimates for the prevalence of children with parent-reported speech-language difficulties. Using Child & Adolescent Health Measurement Initiative (CAHMI) data, Sonik et al. ([2017](#)) found preliminary evidence that suggests this number may be rising. Yet, it is difficult to explain this rise as it can be attributed to many factors, including increased awareness (Sonik et al., [2017](#)).

Gender

Studies of children tend to find that parent-reported speech-language difficulties are about twice as prevalent among boys as among girls (Sonik et al., [2017](#); Raghavan et al., [2018](#)). This approach, however, fails to take into account the gender of people who acquire speech disabilities later in life.

The population who need AAC may be more likely to be transgender or gender non-conforming (TGNC), due to the significant population of autistic people who research suggests are more likely than the general population to identify as TGNC (e.g., Dewinter et al., [2017](#); Shumer et al., [2016](#)). TGNC AAC users may have unique health and communication needs compared to cisgender AAC users (see corbin, [2021](#); Zisk, [2021](#); Tuttleurtle, [2022](#)).

Race and ethnicity

Based on data from the 2012 NHIS supplement, 9.6% of Black children have a voice, speech, language, or swallowing disorder, compared to 7.8% of white children and 6.9% of Latinx children (NIDCD, [2016](#)). Although there are some prevalence data for individual diagnoses that may cause AAC need, there are no clear data on AAC need by race and ethnicity.

Language used in the home

Although it is known that some AAC users do not use English, there are no sufficient data to determine the size of this population or the languages most in demand (Kulkarni & Parmar, [2017](#)).

Type of disability

Appendix C discusses available prevalence data for a variety of diagnoses. However, diagnosis is not necessarily equivalent to disability, and available prevalence data is unreliable.



Without national health-related data on people who need AAC, it is impossible to accurately estimate the number of people who need AAC with a given disability. Nor is it possible to estimate how many people also have one or more of the six other functional limitations currently examined by the American Community Survey (ACS) and other national large population surveys: difficulty with hearing, vision, cognition, ambulation, self-care, and independent living.

Socioeconomic status

Children with any degree of speech or language problems are more likely to live in poverty (31%) than other children with complex medical needs or serious disability (22%). This likelihood increases to 33% for children with “a lot” of speech or language difficulty (Raghavan et al., 2018).

20-22% of children with parent-reported speech-language difficulties live in households experiencing food insecurity, as compared to 11-14% of their peers without any indication of speech-language difficulties (Sonik et al., 2017).

Because large population surveys such as the ACS fail to ask about speech disability, it is impossible to draw any conclusions about socioeconomic factors beyond the lives of children. The only data source that gathers any data meaningfully identifying people who need AAC relative to this topic is the institutional version of the Medicare Current Beneficiary Survey, or MCBS, which only identifies individuals living in institutions who receive Medicare.

II. AAC Access

A. Denials and Delays

The majority of people who need language-based AAC have never been given access to it, even (or especially) in populations with high rates of communication difficulties, such as people with developmental disabilities and people with acquired conditions such as amyotrophic lateral sclerosis (ALS). Clinicians, parents, and caregivers have only begun in the past twenty years to accept that AAC can be used regardless of age, previous language acquisition, or cognitive ability (Light & McNaughton, [2012](#)). Unwarranted assumptions about the capacity or abilities of people who cannot use speech to be understood have historically restricted and continue to restrict access to AAC, and remain widely held in clinical, educational, and other settings as well as by the general public to this day (e.g., Goldman et al., [2021](#)).

“There is currently a substantial gap between what we know about effective AAC interventions and what currently happens in the everyday lives of children and adults who require AAC.” (Light & McNaughton, [2012](#))

Data from nineteen states participating in the National Center and State Collaborative suggest that **well over half of students with communication support needs do not have access to AAC** (Towles-Reeves et al., [2012](#)). Likewise, in a survey of New Mexico primary schools, 1 in 89 students (1.1%) communicated with “severely unintelligible speech,” but only 22% of these students had seen an AAC specialist, and few had access to AAC (Binger et al., [2021](#)). Both of these studies are limited in size, setting, and geographic location, but the results suggest low rates of access to AAC in school settings requiring further investigation.

A study based on the 2012 NHIS supplement found that a little over 10% of individuals who self-reported voice, swallowing, speech, or language problems had received treatment. This figure doubles when limited to those who reported a problem deemed “moderate” or worse (Hoffman et al., [2014](#)). Since the 2012 NHIS supplement did not examine AAC access even as a possible “treatment,” it is impossible to say how many of these people actually received AAC. Nor is it possible to say based on these results why rates of treatment and care are so low.

Although the state of research on access rates to AAC is too sparse to draw specific conclusions, it seems likely that there may be disparities in access to AAC across disabilities and conditions. For example, given the historical limitations on AAC access based on perceived cognitive capacity or intelligence (Light & McNaughton, [2012](#); Goldman et al., [2021](#)) and the attitudes still held by many

clinicians and laypeople alike, people with intellectual and developmental disabilities, including nonspeaking autistic people, may be less likely to have access to robust, language-based AAC. For example, a study of adults with intellectual disabilities in Spain found that only about one-fifth of those with significant communication needs had received any kind of AAC provision and support (García et al., [2020](#)). In 2014, an NCI report found that 83% of nonspeaking respondents – who make up over 25% of all respondents to the NCI-IDD Adult Consumer Survey – communicated primarily with gestures and/or body language, 6% through sign language and/or fingerspelling, and 4% with a communication device; 7% reported they communicate primarily through “other” means (Hiersteiner et al., 2014). This suggests a very low rate of access to robust, language-based AAC among people with I/DD who have no access to spoken communication.

For some people who need AAC, issues of cost, insurance coverage, access to speech-language pathologists (SLPs) and other AAC providers, language barriers, or cultural and familial attitudes may represent additional barriers to AAC access. Asking questions about access to AAC in national healthcare surveys could identify these barriers and determine the extent of their impact on the lives of people who need AAC.

Anecdotal evidence suggests that delays in AAC access vary widely, and the lack can be devastating for people with significant speech disabilities in the meantime. More research is needed to identify periods of delay between identification of AAC need and actual access to AAC, with particular attention paid to factors such as etiologies, age, setting (e.g., nursing homes, institutions), race, class, and language preference.

B. Professional Issues

Despite high acceptance rates of AAC among people with acquired speech disabilities (Fager et al., [2006](#); Fried-Oken et al., [2012](#); Ball, Beukelman, & Pattee, [2004](#)), **there is a tendency to focus on “natural speech restoration” rather than provide support with AAC** (Fried-Oken et al., [2012](#); Light & McNaughton, [2012](#)). Reluctance among professionals to provide meaningful accommodations to people with significant speech disabilities must be investigated and better understood.

Recently, AAC has become acknowledged in the context of temporary medical needs, such as the use of ventilators in intensive care units (ICUs) (Light & McNaughton, [2012](#)). However, in one study, ICU staff report difficulty communicating with patients over one-third of the time, with over half of these cases ranked as “extreme difficulty” or an “inability to communicate at all”; patients only used AAC about 10% of the time (Freeman-Sanderson, Morris, & Elkins, [2019](#)). This indicates **a lack of awareness of AAC even in environments where it is urgently needed.**



AAC providers are not prepared to address the needs of culturally and linguistically diverse people who need AAC. Speech-language pathologists (SLPs) consistently report lacking confidence in their own, and their colleagues', ability to effectively work with culturally and linguistically diverse patients (e.g., Goldman et al., [2021](#); Bridges, 2004; King et al., [2022](#)). Most SLPs identify as white (91.7%) (ASHA, 2020, cited in Mindel, [2020](#)), and only 8% identify as bilingual service providers (ASHA, 2016, cited in King et al., [2022](#)). Yet, a great amount of work is required from SLPs and other professionals to ensure that cultural and linguistic needs are being met. Family members of the AAC user must be involved in assessment, implementation, and training, and each of these stages must respect and value families' priorities and existing communication styles (Kulkarni & Parmar, [2017](#); Parette et al., [2000](#)). The AAC device(s) or communicative strategies themselves must also be tailored to the needs of the user, including icons that look like themselves and members of their community, code-switching capabilities, voices that align with their identities, and words and phrases that reflect their daily life and culture (King & Soto, [2022](#); Mindel, [2020](#); Kempka Wagner [2018](#); Bridges, [2000](#); Rackensperger et al., 2022). When these needs are not met, culturally and linguistically diverse AAC users and their families are more likely to abandon their AAC altogether, leaving them without access to effective communication (Kulkarni & Parmar, [2017](#)). These factors suggest that culturally and linguistically diverse people who need AAC may be less likely to access the AAC they actually need, but the extent to which this disparity impacts them is impossible to determine without reliable, nationally representative data.

III. Pressing Issues

A. Demographic Disparities

Race and ethnicity

Racial and ethnic minorities have higher rates of chronic disabilities than white people (Warner & Brown, [2011](#)), particularly indigenous and Black people, who have much higher and somewhat higher rates of disability than white people, respectively (Mitra et al., [2022](#)). Research also suggests that Black people with acquired disabilities are more likely to experience worse access to services and outcomes (Ellis, [2018](#)) as well as delays in diagnosis and intervention (Qadri et al., [2019](#)). Black and Latinx children receive diagnoses of developmental disabilities much later than their white peers (Mindel, [2020](#)), or may not receive them at all (Boyle et al., [2011](#)). In California, Latinx children have lower rates of autism diagnoses than both white and Black children (Becerra et al., [2014](#)). Delays in diagnosis may result in delays in access to AAC.

From preschool to secondary education, **Black and Latinx children are more likely to receive a speech-related disability diagnosis than their white peers** (Black et al. [2015](#)). Despite this, Black and Latinx children are **less likely to receive intervention services** than their white peers (Black et al. [2015](#)). In order to further investigate this disparity, Pope et al. ([2022](#)) conducted a longitudinal study and found that most white children (63%) were reported to be receiving over 90 minutes of AAC intervention services per week, at the beginning of the study. However, only 29% of Black children were reported to be receiving 90+ minutes of AAC intervention per week. At the end of the two-year-long study, this disparity increased. Notably, 75% of Black children were reported to be receiving less than 60 minutes of AAC intervention services per week.

NCI-IDD data collected in California in the 2017-2018 cycle showed that people who were reported to “prefer” gestures or body language to communicate were more likely to be people of color or multiracial than those who were reported to “prefer” spoken communication. However, people who were reported to “prefer” a communication device were more likely to be white than those reported to “prefer” spoken communication (National Core Indicators, [2018](#)). Not enough data is collected on AAC need and access to determine why this is the case.

In California, despite Latinx children and adults being the largest racial/ethnic group to receive services from the Department of Developmental Services, it has been reported that the per-person spending on Latinx people is the lowest among all racial/ethnic groups (California Department of Developmental Services, [2022](#)).

Although some studies focus on different racial and ethnic subpopulations, such as the connection between African Americans and aphasia (Jacobs & Ellis, [2022](#); Ellis et al., [2017](#)), much more research is needed—systematically and on a larger scale (Ellis & Jacobs, [2021](#))—that delves into racial and ethnic disparities across etiologies.

Language used at home

The ability to use the language of one’s community is a basic human right and part of being able to fully participate in the community. Without this capacity, the ways in which families and communities can connect with one another are significantly impacted (Soto & Yu, [2014](#); Hanson et al., [1997](#)).

Many professionals and parents fear that speaking more than one language in the household will present problems for children with speech disabilities. Their concern is that multilingualism “would be too taxing for children who are already struggling with language, or may further delay the acquisition of one or both languages” (Gutierrez-Clellen, [1999](#)), although this has been disproven (Soto & Yu, [2014](#)). Professional services for children who are raised in multilingual households have typically only been offered in the socially dominant language, yet there is increasing evidence that multilingualism and code-switching are not detrimental to children, even those with speech disabilities (King & Soto, [2022](#)). Indeed, the ability to code-switch and participate in translanguaging practices may increase communication opportunities for multilingual AAC users and enrich their participation in their communities (King & Soto, [2022](#); Kempka Wagner, [2018](#)).

Yet, implementing multilingual AAC intervention continues to be a challenge (Ward, King, & Soto, in press). Although multilingual systems are increasingly common (King & Soto, [2022](#)), users of AAC often do not have access to their community languages on their AAC systems (Tönsing & Soto, [2020](#)). Studies have also shown that there are few opportunities for multilingual individuals who cannot rely on speech alone to participate in multilingual education and have access to multilingual AAC intervention (McNamara, [2018](#)). When developing multilingual AAC intervention, one must consider both the linguistic and the sociopolitical complexities of the individual, their family, and their wider community (Tönsing & Soto, [2020](#); Hanson et al., [1997](#); Bridges, [2000](#); Brady et al., [2016](#)). Interventions lacking these considerations are much more likely to result in abandonment of AAC, ultimately further isolating the person with a speech disability (Kulkarni & Parmar, [2017](#); Mindel & John, [2018](#)).

Very few AAC systems and supports are designed with indigenous people in mind, culturally or linguistically. Essential efforts are being made to develop AAC systems that are culturally and linguistically appropriate for indigenous populations, such as for users of the Lakota language (Callahan & Hansen, [2022](#)).



B. Education and Literacy

Recent studies on AAC users in educational settings have had alarming results. In a sample population of mostly primary school-age students with intellectual and developmental disabilities who use AAC, results showed that only 1.1% of students using AAC without access to speech were placed in general education classrooms alongside nondisabled students. Only 3% read with comprehension, and only 12% read individual words (Erickson & Geist, [2016](#)).

More research is needed on both educational segregation and literacy rates for children who need AAC. It is worth noting that without supports like AAC, “children with communicative disabilities do not interact with peers any more frequently in inclusive settings than they do in segregated settings” (Hanson et al., [1997](#)), making access to AAC and normalization of AAC in the child’s social environment critical to integration efforts.

Apart from experiencing higher rates of segregation and inequitable educational opportunities, students who need AAC are known to experience bullying, restraint, and expulsion. More data on the experiences of students with significant speech disabilities is needed.

The U.S. Department of Education’s Office of Special Education and Rehabilitative Services (OSERS) is well-positioned to conduct inquiries into the adverse educational experiences of students who need AAC.

C. Guardianships and Institutionalization

Although it is likely that people who need AAC are subjected to guardianships at a higher rate than people who do not, even with the same or similar disabilities, there is currently no data on guardianships by AAC need.

A report from the 2014 NCI-IDD reveals that “nonverbal” respondents were more likely to “require 24-hour on-site support or supervision” (70%) than speaking respondents (52%), and more likely to be institutionalized (12% of nonspeaking respondents, versus 2% of speaking respondents) (Hiersteiner et al., 2014). Based on this, it seems likely that people who need AAC are the last group of people to be deinstitutionalized post-*Olmstead*. More data are needed to better understand the situation inside institutions and other group settings.

D. Employment, Socioeconomic Status, and Benefits

Only a small percentage of individuals who need AAC are employed (McNaughton & Arnold, [2010](#)). Because studies have found that employment plays a key role in satisfaction and quality of life (e.g., Rifkin, 1985, as cited in McNaughton & Arnold, [2010](#)), and since employment is a goal for many AAC users (Bryen, Potts, & Carey, [2006](#)), taking steps to increase the percentage of AAC users in the workforce and supporting them in positive ways should be prioritized.

Research finds that people with significant speech disabilities have fewer job options and opportunities than their peers who have no trouble communicating with others (McNaughton & Bryen, [2007](#)).

Research is needed to identify the number of people with significant speech disabilities who do not have access to competitive integrated employment (CIE), who may be paid subminimum wage and isolated from nondisabled people.

Low-income status, public health insurance, and lower maternal education are each associated with a higher prevalence of developmental disabilities (Boyle et al., [2011](#)). Yet, low-income families are often denied access to information about services, and may be less likely able to access services even when they know about them due to various reasons, including time constraints, transportation issues, distrust of medical professionals, or lack of insurance (e.g., Mindel, [2020](#)). The cost burden of AAC—which includes not just technology, but also training for the user and conversational partners—may present a significant barrier to low-income people who need AAC. Insurance coverage varies by the type of AAC. For example, “dedicated” AAC devices, such as speech-generating devices, are more likely to be covered by Medicare, Medicaid, and private insurance because insurers consider this technology to be “durable medical equipment,” or DME. “Non-dedicated” AAC devices, such as tablet-based AAC devices, including AAC apps, are usually not covered by insurance because they do not fall under the category of DME (White & McCarty, [2011](#); Satterfield, [2015](#)). This may lead to paradoxical situations where a “dedicated” AAC device with more drawbacks is cheaper for a family than a tablet that could be used in more situations (Brady et al., [2016](#)).

As previously mentioned, the only administrative data set for beneficiaries of benefits in the U.S. that asks about speech disability is the institutional version of the MCBS; only people living in institutions receiving Medicare are currently counted. No other data on benefits and people who need AAC is available, and the only other data available on their socioeconomic status is gathered only for children via the NSCH.

E. Healthcare

People who need AAC are likely to have multiple significant disabilities. The inability to use speech to express oneself compounds and exacerbates other co-occurring disabilities and healthcare needs, especially when AAC is not available or when AAC use is disrespected or disregarded by providers.

Using 2012 NHIS data, Stransky et al. (2018) found that 79.9% of people with speech disabilities have one or more chronic conditions, compared to 50.1% of people without; 48.3% of people with speech disabilities report poor or fair health, as compared to 11.2% of people without. Although people with speech disabilities use healthcare services more frequently than people without, they have greater difficulties in accessing care (30.8%) than people without speech disabilities (16.1%). 49-56% of children with parent-reported speech-language difficulties, though not necessarily children who need AAC, lacked full access to healthcare services, according to a cross-sectional study of multiple national surveys, including the NSCH and SIPP (Sonik et al., 2017). Finally, a report from the 2014 NCI-IDD shows that “nonverbal” respondents report worse overall health than speaking respondents (Hiersteiner et al., 2014). These findings suggest that reliable and comprehensive health-related data for this population are urgently needed.

Hurtig, Alper, and Berkowitz (2018) found that patients with speech disabilities are three times more likely to experience preventable adverse events than those without. They estimated that preventable adverse events could be reduced by 671,440 cases per year, leading to annual savings of \$6.8 billion. Considering these findings, more research should be done on preventable adverse events in this population.

Adult nonspeaking autistic AAC users report having AAC devices taken away from them while in the hospital or having AAC communication entirely ignored by medical staff (Donaldson, corbin, & McCoy, 2021; corbin, 2021).

F. Violence and Harm

A study of adults who use AAC found that **45% report experiencing crime or abuse** (Bryen, Carey, & Frantz, 2003). Nearly all victims (97%) reported knowing the perpetrator, 71% reported being victimized multiple times, and two-thirds reported experiencing multiple types of victimization. Only about one-fourth reported their experiences to the police (Bryen, Carey, & Frantz, 2003).

In 2012, the Disability & Abuse Project created a National Survey on Abuse of People with Disabilities which included people with speech disabilities as a disability group. According to the



survey report, **67.1% of respondents who had a speech disability reported being victims of abuse**, and close to half of respondents (43.8%) with speech disabilities reported having experienced abuse ten or more times. 66.8% of people with speech disabilities reported having experienced bullying, an overwhelming 89% of that population experienced bullying on multiple occasions. One quarter (24.6%) of victims of sexual assault had a speech disability, although the report notes that this figure seems underreported (Baladerian et al., [2013](#)).

These figures are grave, especially given that abuse is generally underreported and that people with disabilities are more likely to be abused and tend to have more trouble being taken seriously by law enforcement than nondisabled people (Baladerian et al., [2013](#)). Additionally, many people who need AAC likely lack the ability to communicate their experiences, especially when their need for AAC is unmet.

G. Social Support Systems

“Nonverbal” respondents to the 2014 NCI-IDD reported more anxiety about their safety, less community engagement, and significantly less ability to make choices about their lives (Hiersteiner et al., 2014).

In Australia’s Survey of Disability, Ageing, and Carers (SDAC), over half of caregivers reported that they provided communication support to the main person they assisted (Australian Bureau of Statistics, [2019](#)). With this number so high, it seems a missed opportunity that Caregiving in the U.S., the largest survey assessing caregiver characteristics in the U.S., does not ask whether caregivers provide communication support (National Alliance for Caregiving & AARP, [2020](#)). Nor does the primary federal survey on caregiving, the National Study of Caregiving (National Institute on Aging, [n.d.](#))

There is no other available data on social support structures for people who need AAC, including marriage, friendships, family, or caregivers. Given the isolating nature of significant speech disabilities, answering this question with reliable data is paramount.