

AAC COUNTS

AAC Counts I: The Urgent Need for Better Data About People with Significant Speech Disabilities

AAC Counts - Part I: The Urgent Need for Better Data 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. Introduction and Background ([jump](#))

- A. The Problem
- B. Towards Data Equity
- C. Ending the Silence

II. Existing Data Sources ([jump](#))

- A. Federal Sources
- B. State Sources
- C. California Sources
- D. International Sources

III. Considerations in Counting and Surveying People Who Need AAC ([jump](#))

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. Introduction and Background

A. THE PROBLEM

Over one dozen U.S. federal government agencies are involved in collecting, compiling, or analyzing data on people with disabilities.¹ However, **none collect data on the demographics and needs of the at least five million children and adults in the United States who need AAC to be heard and understood by others.**

In the absence of any systematically collected data on people who need AAC, one way to estimate the total U.S. population who needs AAC could be to add up the estimated number of people in each disability category that commonly experiences speech disability. **Figure 1** on the next page (and the table in **Appendix C**) reveal the results of that exercise. However, using diagnostic-based prevalence data to calculate this estimate has numerous shortcomings, and the resulting estimate cannot be assumed to be accurate. Why?

First, not all relevant diagnoses or conditions have estimates of the prevalence of speech disabilities within that group, even when the population is a large one. For example, the number of people with dementia or Alzheimer's in the United States was at least 2.4 million in 2012 (U.S. Census Bureau, [2012](#)), but there do not appear to be any reliable estimates of the percentage who experience significant difficulty being understood (Crema, [2009](#); McAuliffe et al., [2019](#)).²

Second, when data are available within diagnostic categories on the prevalence of AAC need, such estimates are often over a decade old. When lifespans are increasing for many parts of our population, old data may not reliably reflect the status quo (e.g., Boyle et al., [2011](#)).

¹ These include the White House Office of Management and Budget (OMB); U.S. Department for Health and Human Services's National Center for Health Statistics, Centers for Medicare and Medicaid Services (CMS), National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), Administration on Disabilities (AoD), and Independent Living Administration (ILA); U.S. Centers for Disease Control and Prevention's National Center on Birth Defects and Developmental Disabilities, Division of Human Development and Disability; U.S. Social Security Administration; U.S. Department of Labor's Bureau of Labor Statistics; U.S. Department of Commerce's U.S. Census Bureau and Bureau of Economic Analysis; and the U.S. Department of Education's National Center on Education Statistics and Office of Special Education and Rehabilitation Services (OSERS), among others.

² Advances are being made in supporting some individuals with dementia or Alzheimer's disease to use AAC to augment their memory and language skills (e.g., Fried-Oken et al., [2012](#); May et al., [2019](#)). The availability of data on such persons could inform such research.

Third, when studies do calculate the proportion of the group that may have a significant speech disability, rarely do they use the same methods or adhere to the same standards to do so, and the criteria they use to define significant speech disability or the need for AAC is not always clear.

Finally, calculating an estimate using diagnostic prevalence models will not account for people with multiple diagnoses and co-occurring conditions, which may result in an overestimate of the population. Ultimately, **prevalence data are not well-suited and should not be relied upon in producing an accurate estimate of the number of people in the U.S. who need AAC.**

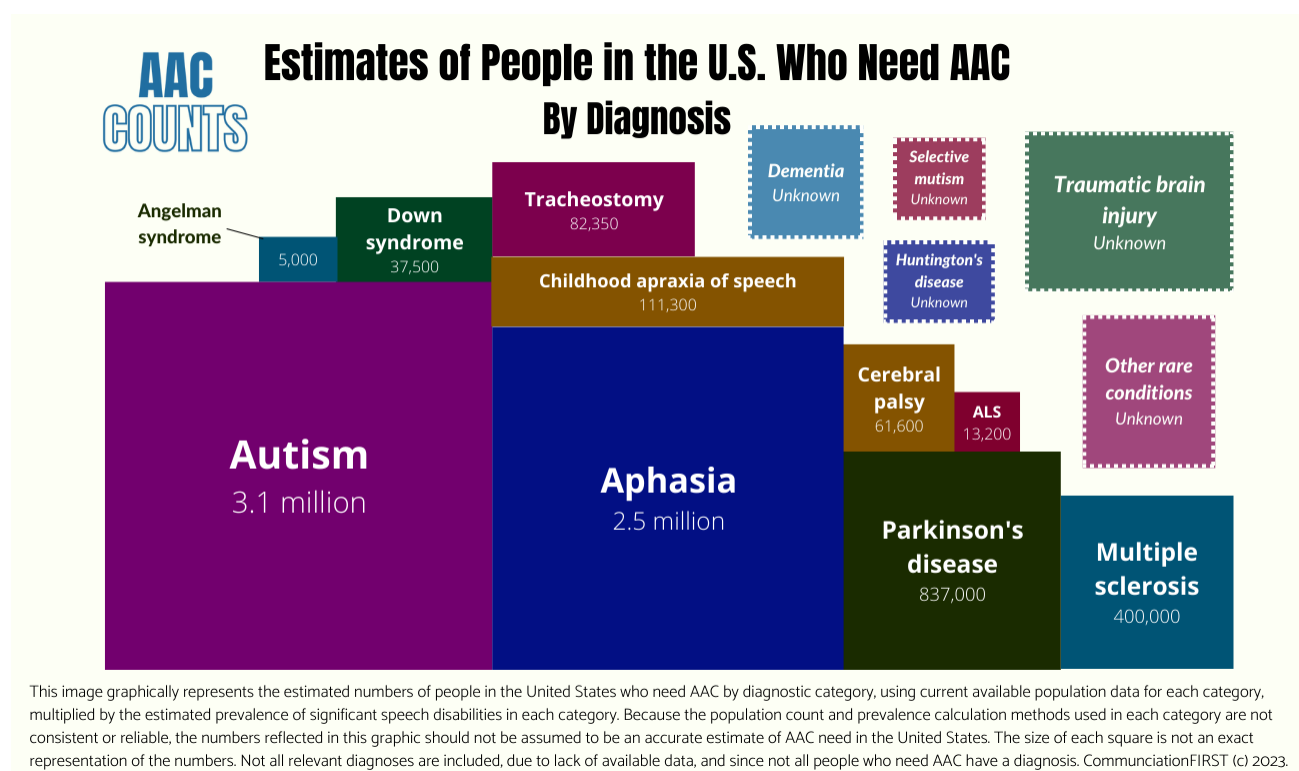


Figure 1: Graphical representation of figures in Appendix C estimating the number of people with certain diagnoses who may need AAC.

Without reliable national and state level data about the population of focus, it is impossible to answer essential questions such as:

- What is the size of this population and its characteristics, in terms of age, gender, race, ethnicity, language used in the home, type of disability, and socioeconomic status?
- What are the most pressing issues facing this group as a whole?
- How many people who need it continue to lack access to AAC?



- Are there gender, racial, language, or economic disparities in accessing AAC?
- What percentage of students who need AAC in the past year:
 - ...had access to AAC sufficient to communicate effectively with their classmates and participate in classes and extracurricular opportunities?
 - ...were educated in fully inclusive settings versus more restrictive settings?
 - ...were reading at or above grade level?
 - ...graduated or otherwise left public school with the AAC they need, and the requisite literacy skills to do so?
 - ...graduated from high school with a standard diploma?
 - ...attended college?
- How many have their rights terminated and are subjected to conservatorships or guardianship?
- What percentage in the last year:
 - ...resided in integrated community, group homes, or institutional (including juvenile justice and adult corrections) settings?
 - ...were employed at least 20 hours per week?
 - ...had earnings at or above the median income level for where they live?
 - ...had income at or below the federal poverty level (FPL)?
 - ...had public or private health insurance, or were uninsured?
 - ...received SSI, SSDI, Social Security Retirement, or TANF benefits?
 - ...received or reported an unmet need to access Medicaid home and community-based or institutional long term services and supports?
 - ...experienced disability-related bullying, harassment, sexual violence, abuse, neglect, exploitation, violence, threats, or substantial harm?
- How many are married, have opportunities to experience romantic relationships, or have meaningful friendships?

Federal survey data offering answers to many of these questions already exist with regard to most individuals living in the U.S., including those with one or more of the six categories of functional limitations used by the U.S. Census Bureau to identify disability. These categories will be discussed in more detail throughout this report.

Failing to track this population, its demographics, living conditions, and well-being makes it difficult for policymakers to identify and appropriately address the unmet needs and challenges of people who need AAC. It further exacerbates and complicitly sanctions the harsh lifelong discrimination—substandard education, institutionalization, poor healthcare, and social death—such individuals must endure. This is untenable in 2023. Without accurate data and



statistics, public policies and programs will remain woefully inadequate, and improving the life opportunities of people who need AAC will remain virtually impossible.

Not counting those who struggle most to have a say in life renders an insular class of people more invisible and powerless.

Many marginalized populations experience particular barriers to both accessing and using AAC, including: Black, indigenous, and other communities of color; those whose community language is not English; immigrants, especially those who are undocumented; and people living in institutions. **This report attempts to illustrate the systemic injustices they face, as well as the need for data that can help to identify and rectify these injustices.**

Thus, the impetus for this project was to begin to address the longstanding data inequities facing people with significant speech disabilities in the United States. Its aim, therefore, is very much aligned with the federal government’s current emphasis on ensuring that the data it gathers can be brought to bear in eradicating the most intransigent disparities for individuals and communities living at the intersection of race, disability, age, ethnicity, gender, transgender identity, sexual identity, language, income inequality, and other socio-economic variables.

B. TOWARDS DATA EQUITY

The COVID-19 pandemic and the racial reckoning that began in 2020 continue to remind the nation of the urgent need to identify, better understand, and develop comprehensive, evidence-based strategies to combat the systemic racism and multiple forms of oppression experienced daily by many—and relatively soon most—people in the U.S. who live at the intersection of race, disability, age, ethnicity, gender, transgender identity, sexual identity, language, income inequality, and other socio-economic variables.

To ameliorate the immense social inequities and disparities laid bare by the pandemic and the brutal police killing of George Floyd, President Biden issued the [Executive Order on Advancing Racial Equity and Support for Underserved Communities](#) immediately upon taking office to launch a whole-of-government effort to incorporate the principle of equity throughout the federal government. Among other things, the Order recognizes “the ability to conduct equity assessments—i.e., to understand the impact of federal policies on equity outcomes—and identify and remove barriers to equitable access to government programs is contingent on gathering the necessary data.” In order to enhance the nation’s capacity and commitment to collecting and using “equitable data” to inform every facet of federal policy, the President ordered the creation of a



working group to: (a) identify inadequacies in federal data collection policies, programs, and infrastructure; and (b) lay out a strategy for increasing data available for measuring equity and representing the diversity of the American people (Exec. Order No. 13985, [2021](#)). The Administration defines the term “equitable data” to mean:

“Disaggregated data ... that can be broken down and analyzed by race, ethnicity, gender, disability, income, veteran status, age, or other key demographic variables (and) offers more precise statistical indicators of population well-being, as well as insight into who can and cannot access government programs and whether benefits and services are reaching underserved and underrepresented communities” (Equitable Data Working Group, [2022](#)).

The repeated failure to collect and press equitable data into use comes at a high and unjustifiable price for the individuals, families, and communities most affected, as well as for our democracy. **Collecting reliable data on a population that is as out of sight, out of mind, excluded, and ostracized as people with significant speech disabilities is certainly a complicated and daunting task for the federal government, California, and other states to engage. Yet, it is no longer tenable for this to serve as the stated or or unstated reason for why this is not done.**

A path to data equity must identify the obstacles and, in turn, identify and pursue meaningful solutions.

Estimating the number of people in the United States who need AAC has thus far been challenging for several reasons.

1. The disabled population tends to be counted through survey questions that ask about functional limitations rather than diagnosis, but **there is no adequate and widely used functional limitation question with regard to this population.**
2. At least two dozen different medical conditions or diagnoses may cause or be associated with varying degrees of difficulty using speech to communicate. Furthermore, the same diagnosis that causes AAC need in one person may not in another. Therefore, the only path to a reliable population estimate is **collecting data on functional speech limitation**, not on a particular set of diagnoses.
3. The need for AAC can occur from birth or at any time in a person’s life, so there are **no age-related proxy indicators** that could simplify data collection (e.g., kindergarteners, Social Security recipients, people with developmental disabilities). Nor is it sufficient to use data from service providers such as Medicaid or the Office of Special Education and

Rehabilitative Services; even when data is collected on people who need AAC by these providers, not all people who need AAC receive services.

4. Alternative communication modalities, systems, tools, and supports vary greatly, and can range from gesturing to homemade aids to digital speech-generating devices. This precludes the possibility of estimating the number of AAC users with data from AAC manufacturers or suppliers.
5. **The majority of people who need AAC have never been given access to it** (see, e.g., Kent-Walsh & Binger, 2018; Kenney & Kogan, 2011). This is in part due to outdated candidacy models and assumptions about prerequisites to AAC use (Goldman et al., 2021; Stuart & Ritthaler, 2008). Scant attention has been given to children and adults who may need AAC on an occasional or intermittent basis, including those with multiple sclerosis, traumatic brain injury, psychiatric labels, and other conditions currently not often thought to be associated with the need for AAC (Zisk & Dalton, 2019).
6. **There is a professional and societal tendency to dismiss the voices of those who cannot use speech alone to communicate.** This might be called [speechism](#), or ableism more broadly. At least in part, information has not been gathered because information has not been valued.

Large population surveys are the most effective and equitable way to gather comprehensive and reliable data on people who need AAC. Thus, questions on functional speech limitations must be included on large-scale population surveys addressing disability. Policy makers at the federal, state, and local levels as well as advocacy organizations must have access to such data in order to identify and responsibly address the barriers and discrimination confronting these individuals. Real and perceived methodological challenges exist to achieving this aim, but cannot remain excuses for doing nothing.

Data equity for people who need AAC must also take into account the histories, lived experiences, and multiple forms of oppression across all disenfranchised communities.

Black, indigenous, and other people of color, those whose community language is not English, and immigrants are particularly vulnerable to denial of resources, services, and opportunities, and AAC access is no exception. Yet, there is little known data on people who need AAC by race, immigration status, and community language, and what does exist suggests significant disparities.



There is also a troubling lack of data on AAC needs and access in institutionalized residential settings, where people are more likely to be assumed to be “too disabled” to need AAC. It seems likely that when an individual lacks access to AAC, they are more likely to remain institutionalized indefinitely. It is also likely that people who need AAC are the last group of people to be deinstitutionalized post-*Olmstead*, a suspicion supported by what data is available on people who cannot rely on speech to be understood living in institutions. For example, nationwide, roughly 39 percent of all nursing home residents (total 1.5 million) had speech disabilities (Ne’eman et al., 2022). This percentage varied little across all age groups, except the youngest: of the 1,595 nursing home residents under age 19, 93 percent had speech disabilities. The same pattern held for those with receptive communication disabilities. Moreover, nearly 67,500 people were living in Intermediate Care Facilities for individuals with intellectual and developmental disabilities (ICF/IDD) in 2019 (RISP, [n.d.b](#)). Individuals who live in ICF/IDDs have significant and multiple disabilities, and most have little to no understandable speech and need a range of AAC strategies and support to express themselves. Despite these facts, no known data exist on how many nursing home and ICF/IDD residents need AAC, let alone how many actually have access to it.

Nor is there any data regarding people who need AAC who are incarcerated in juvenile justice and adult correctional facilities. The lack of data means that there is no way to know how many such individuals are incarcerated, whether their needs are being met, whether they can effectively communicate, and are being afforded their right to be kept free from harm while serving time. This, too, is untenable.

Without adequate, equitable, demographic data at either the federal or state levels on people in the U.S. who require AAC to effectively communicate, it is impossible for policy makers to ascertain how widespread the unmet needs, inequities, and threats are posed to such persons. By failing in its duty to collect such data, the government is operating in the dark in respect to this population, and abandoning its most basic duty to do no harm. Instead, it perpetuates it.

C. ENDING THE SILENCE

People who need AAC have long been regarded as disposable, silent, and powerless. This assumption creates a vicious cycle, representing both cause and effect: when a person is assumed to lack agency, they are not given the tools to exercise it; when a person does not have the tools to exercise agency, they are assumed to lack it. Testimonials from the community point to high levels of institutionalization, medical neglect, abuse, and trauma—and these testimonials come from those with enough access to AAC to give voice to their stories. What stories are missing from people with significant speech disabilities who lack access to effective communication, to community, to justice?

What stories are missing from people with significant speech disabilities who lack access to effective communication, to community, to justice?

It is imperative to begin counting and including people who need AAC as a population that matters, as a disability group under the broader umbrella of communication disabilities, and as a historically marginalized population that requires more focused attention from policymakers to rectify historic inequities.

Loneliness and Trauma

Loneliness, including its deleterious effects on physical and psychological effects, is itself both cause and consequence of serious trauma. Trauma theorists such as Dori Laub, Judith Herman, and Art Blank suggest that trauma is defined by the experience of helplessness in the context of a breakdown in the “ordinary systems of care that give people a sense of control, connection, and meaning” (Herman, 1992, p. 33): that is, a breakdown of the ability to connect and communicate with other human beings. We rely, Laub argues, on a “matrix of two people, a self and a resonating other” in order to establish a sense of self and a sense of the world as a place in which we can safely exist (Laub, [2013](#)).

In other words, communication is not only a human right, but a basic need for survival of the self. **Without effective communication and understanding, human beings face death of the self.** For people who cannot rely on speech to be heard and understood, this death of the self may become an everyday experience, but it will never become less traumatic. Indeed, this repetition only intensifies the effects of trauma, making it both more disabling and more difficult to heal.

How many people with significant speech disabilities have been exposed to this trauma? How long did they have to face this trauma before they were able to access AAC? How many are still being denied this foundational part of human life? Was this trauma compounded with others, such as caregiver abuse, medical neglect, or

incarceration in prisons, jails, or institutions? How does this trauma intersect with other potentially traumatizing life experiences, such as marginalization due to negative racialization? These critical questions cannot be answered without reliable and comprehensive data on people who need AAC.

II. Existing Data Sources

A variety of disability-related data is collected at the local, state, federal, and international levels. Efforts are conducted by governments and non-governmental parties. **Most disability data sources do not collect any data on speech-related disabilities and conditions. Where they do, the results generally fail to adequately capture the population of focus.** This section describes the key sources of disability data in the United States and how well they do at counting people with significant speech disabilities.

A. FEDERAL SOURCES

Federal data has been broadly categorized by six disability groups:

- **Hearing difficulty:** Deaf or having serious difficulty hearing
- **Vision difficulty:** Blind or having serious difficulty seeing, even when wearing glasses
- **Cognitive difficulty:** Because of a physical, mental, or emotional problem, having difficulty remembering, concentrating, or making decisions
- **Ambulatory difficulty:** Having serious difficulty walking or climbing stairs
- **Self-care difficulty:** Having difficulty bathing or dressing
- **Independent living difficulty:** Because of a physical, mental, or emotional problem, having difficulty doing errands alone such as visiting a doctor's office or shopping

Even though two of the six disability-related questions focus on vision and hearing disabilities, none focus on the third major communication disability—speech. Many persons who require AAC may have co-occurring disabilities or long-term conditions that are associated with one or more of these six disability groups and can self-report as such on current surveys. However, there are other individuals who need AAC solely due to conditions that impact their mouth or throat, and do not have any of the six types of disabilities. Regardless of whether those needing AAC fall into one or more of the six disability buckets, however, is beside the point.

Expressive communication is as paramount to daily living and community participation as any of the six disabilities currently tracked by federal surveys, but because it is not tracked as a functional limitation by major federal surveys, the data available regarding other disability groups is not available for people with speech disabilities, including those needing AAC.

This report is centered on people who have little to no understandable speech and must have access to AAC to effectively communicate. We must point out, though, that major criticism and concerns have been raised by the disability community and others regarding these six disability categories as resulting in a significant undercount or a complete failure to count individuals with

limitations associated with not only speech disabilities but learning disabilities, chronic health conditions, some mental health conditions, and many neurological conditions, among others (see, e.g., Henderson, [2011](#)). The problems we identify as well as the larger one are, therefore, real and demand actions and solutions.

American Community Survey (ACS)

- U.S. Census Bureau
- Federal - Annual - Surveys those living in the community and group living settings

The United States Census Bureau's American Community Survey (ACS) is the most widely used survey for disability research in the United States. The survey asks questions about the above-mentioned six types of functional limitations, but it does not identify people with speech disabilities (U.S. Census Bureau, [2022d](#)). Many people with speech disabilities may be included under the six disability categories, but some may not be included under any of the categories. As a result, it is impossible to determine from the ACS how many people in the United States need AAC.

Data made available from the ACS ranges from population demographics (e.g., sex, race, Hispanic or non-Hispanic ethnicity, age), to economic characteristics (e.g., employment status, work experience, occupation and industry, type of commute, educational attainment, earnings in the past year, and poverty status), to services received (e.g., health insurance, SSI, food stamps). Data can be geographically delineated by state and by local area. This information is vital for creating, enforcing, and funding effective public policy.

The ACS is one of the few federal surveys that includes people who are institutionalized—a significant subpopulation of people who need AAC. In 2006, it began including both institutional and non-institutional groups in its sampling frame (U.S. Census Bureau, [2022c](#)).

National Health Interview Survey (NHIS)

- Centers for Disease Control and Prevention (CDC)
- Federal - Annual - Institutionalized people excluded

The NHIS, conducted by the CDC, began using the Washington Group question on communication as a functional limitation in 2019 (National Center for Health Statistics, [2019](#)):

“Using your usual (customary) language, do you have difficulty communicating, for example understanding or being understood?” Possible responses include “no difficulty,” “some difficulty,” “a lot of difficulty,” and “cannot do at all” (Washington Group, [2020](#)).



Yet “difficulty understanding” and “difficulty being understood” describe two very different functional limitations, and though a distinction between the two is made for children, it is not made for adults, confounding any data collected by this question. The United Nations Children’s Fund (UNICEF)’s international Multiple Indicator Cluster Surveys (MICS), conducted among 70 low- to middle-income countries, also uses this question (UNICEF, [n.d.](#)).

The NHIS also asks whether children have difficulty being understood by other people in their household, and by people outside of their household, an important acknowledgment that communication disability is contextual, and may change depending on conversational partners and environment. However, it does not ask this question of adults.

No questions are asked on access to AAC. Children under 5 years of age and people living in group or institutional settings are both excluded from the NHIS.

Data from the NHIS and other national health surveys, discussed in greater detail below, provide vital population-level information about the health of Americans, possible disparities, and effects of service and care (Raghavan et al., [2018](#)). Without this data, there is little hope for understanding the health and healthcare situation of people who need AAC in the U.S.

1994-1995 National Health Interview Survey on Disability (NHIS-D)

- Centers for Disease Control and Prevention (CDC)
- National Institutes of Health (NIH)
- Federal - Unique - Institutionalized people included

The Americans with Disabilities Act (ADA) was signed into law in 1990, and major health reform efforts were underway. Policymakers required data on both fronts. In part as a response to this lack of data, the NHIS-D in 1994-1995 collected the richest data on disability in the history of the United States.

Phase I included multiple questions on significant speech disability, along with questions on sensory and mobility disabilities (National Center for Health Statistics, [1994](#)):

- Do [names of people ages 5+] have difficulty communicating so that PEOPLE OUTSIDE OF THE FAMILY understand? [*To be read if necessary: Do not include language problems.*]
- Does [name] have any difficulty communicating so that FAMILY MEMBERS understand?
- Does [name] have difficulty communicating [name’s] basic needs, such as hunger and thirst, to family members?

- How old was [name] when [name] first had difficulty communicating with other people?
- Is [name] expected to have this difficulty with communication for at least 12 months longer? *[If obvious, mark without asking.]*
- What condition causes [name's] difficulty communicating with other people?

Phase II, which followed up on the NHIS-D Phase I, also asked whether an individual would need a voice synthesizer to be able to work. Furthermore, “Sample person’s speech problem” could be provided as a reason for the use of a proxy responder (National Center for Health Statistics, [1995](#)).³ No survey similar in purpose and scope to the NHIS-D has been attempted since.

National Health Interview Survey (NHIS) Supplement on Voice, Swallowing, Speech, and Language Problems (2012, 2022)

- 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

This 2012 supplement to the 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](#)). Data collected included etiology, frequency, duration, severity, age of onset, services and/or care received, effect of care on quality of life, and change over time.

Some of the questions asked in the 2012 supplement on voice, swallowing, speech, and language problems were asked again during the 2022 cycle, for which data is not yet available at the time of this report (National Center for Health Statistics, [2022a](#)). Questions about etiology, duration, and age of onset were removed. No questions were asked on access to AAC, and the same exclusions of children under 5 and institutionalized people apply.

Survey on Income and Program Participation (SIPP)

- U.S. Census Bureau
- Federal - Now annual - Institutionalized people excluded

³ For more on the NHIS-D and proxy response, see [Part III](#) of this report.

The SIPP previously included a speech disability-related question in topical modules in 2008 and in the 2014 SSA Supplement, but this has not since been used (U.S. Census Bureau, [2017](#)). The question identified respondents with serious speech difficulty and then asked whether they would rate the difficulty as “nonsevere” or “severe.” This question could be modified, for example, to ask respondents who indicate they have one or more disabilities how many people are able to understand their speech due to disability—i.e., no one; a few – <10; some - 10-24; many – 25-50; a lot – over 50. **Another possible way to phrase a question is the frequency of when a stranger is likely to understand their speech. All or some of those who answer the question should be asked whether they currently use or have an unmet need for AAC.**

The SIPP adds a few disability categories to the six standard groups: (a) developmental delay limiting ordinary activity for children under 5, (b) a limited ability to play with other children of the same age for children ages 5-14, (c) a limited ability to do regular schoolwork for children ages 5-14, (d) limited in the kind or amount of work they are able to do, (e) difficulty finding or keeping a job, and (f) prevented from working (U.S. Census Bureau, [n.d.](#)). None of these categories are inclusive or exclusive enough to be used to identify participants with significant speech-related disabilities who need AAC.

The 2014 SIPP collected an array of data on children under 3 as well as ages 3 to 4 who have difficulty seeing, hearing, playing, and/or moving about. However, no comparable data were collected on children in these age groups who have any degree of difficulty speaking.

National Health and Nutrition Examination Survey (NHANES)

- Centers for Disease Control and Prevention (CDC)
- Federal - Annual - Institutionalized people excluded

The CDC’s **National Health and Nutrition Examination Survey (NHANES)** uniquely combines interviews and physical examinations to gather data on health. Starting in the 2019-2020 survey cycle, the NHANES began including the following questions on communication:

- When {you speak/SP speaks}, {do you/does he/does she} have difficulty being understood by people **inside** of this household? [Would you say {you have/SP has}: no difficulty, some difficulty, a lot of difficulty, or cannot do at all?]
- When {you speak/SP speaks}, {do you/does he/does she} have difficulty being understood by people **outside** of this household? [Would you say {you have/SP has}: no difficulty, some difficulty, a lot of difficulty, or cannot do at all?] (CDC, [2020](#)).

No questions are asked about AAC need. Institutionalized people are excluded from the dataset.



Behavioral Risk Factor Surveillance System (BRFSS)

- Centers for Disease Control and Prevention (CDC)
- Federal - Annual - Institutionalized people excluded

The CDC's **Behavioral Risk Factor Surveillance System (BRFSS)** gathers data on health behaviors and risks, but does not ask questions about speech limitations (CDC, [2022](#)). This is especially harmful since the BRFSS is the data source for the CDC's the Disability and Health Data System (DHDS), an online source of state-level data on adults with the six types of disabilities that the federal government uses for survey purposes. The DHDS is used to identify and reduce health disparities. The failure to include questions on speech disabilities and the need for AAC makes it impossible for health experts, individuals, and policymakers to identify and remedy the risks persons face, *precisely because* they have little to no understandable speech.

National Survey of Children's Health (NSCH)

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

The NSCH, led and funded by the HRSA, includes the following questions on communication:

- Has a health care provider, including a doctor, or an educator, ever told you that this child has a speech disorder or another language disorder?
 - If yes, does this child currently have the disorder?
 - If yes, is the disorder mild, moderate, or severe? (The Child & Adolescent Health Measurement Initiative, [n.d.b](#))

No questions are asked about AAC need. Institutionalized children are excluded from the dataset.

National Health and Aging Trends Study (NHATS)

- National Institutes of Health (NIH)
- Federal - Longitudinal - Institutionalized people partially excluded

The **National Health and Aging Trends Study (NHATS)**, funded by the NIH, is a longitudinal survey of elderly people in the U.S. receiving Medicare. The NHATS includes the following question :



- “In the last month because of {your/SP's} health, did {you/he/she} have any problems in speaking or in making {yourself/herself/himself} understood when {you talk/he talks/she talks}?” (National Institute on Aging, [2022](#))

Although the NHATS does gather some information on institutionalized elderly people, it only gathers a partial data set compared to non-institutionalized respondents, and does not attempt to collect direct responses under any circumstances (National Institute on Aging, [n.d.](#))

Transformed Medicaid Statistical Information System (T-MSIS)

- Centers for Medicare & Medicaid Services (CMS)
- All U.S. states - Monthly - Includes institutionalized people who receive Medicaid

CMS requires U.S. states to utilize the Transformed Medicaid Statistical Information System (T-MSIS) in collecting Medicaid and Children’s Health Insurance Program (CHIP) claims data, including a provider taxonomy code for “Augmentative Communication Clinic/Center” when such a service is used by a recipient. The T-MSIS does not otherwise collect data on speech disabilities (CMS, [n.d.d.](#)). In addition, both between-state variations in data collection and high rates of missing data mean that data quality issues limit the potential usefulness of T-MSIS data (Saunders & Chidambaram, [2022](#)).

Minimum Data Set (MDS)

- Centers for Medicare & Medicaid Services (CMS)
- U.S. Department of Health and Human Services (HHS)
- Federal - Quarterly - Residents of Medicaid- and Medicare-certified nursing homes

The CMS’s Minimum Data Set is a collection of data on residents of nursing homes and includes two questions of relevance to this population: one question on “speech clarity” and one on residents’ ability to make their needs and wants understood, via “verbal and non-verbal expression.” The MDS does not report on assistive device use or access to AAC (CMS, [n.d.b.](#)).

Medicare Current Beneficiary Survey (MCBS)

- Centers for Medicare & Medicaid Services (CMS)
- Office of Enterprise Data and Analytics
- All U.S. states - Longitudinal - Different surveys for people living in community versus institutions



The Medicare Current Beneficiary Survey (MCBS), sponsored by CMS's Office of Enterprise Data and Analytics, is a survey that has been conducted continuously for more than thirty years, amassing more than one million interviews (CMS, [n.d.a](#)). Two different questionnaires are used for people living in the community versus people living in institutions. Both beneficiaries living in the community and institutions responding on behalf of resident beneficiaries may indicate expenditures for hearing or speech devices, though the two are categorized together and cannot be disaggregated (CMS, [n.d.c](#)). Institutions are asked the following about residents' functional speech limitations:

- Which statement best describes how effective (SP) was at making (herself/himself) understood on or around (HS REF DATE)? Was (she/he) always understood, usually understood, sometimes understood, or rarely or never understood? (CMS, n.d.d)⁴

IDEA Data Center

- Office of Special Education and Rehabilitative Services (OSERS)
- U.S. Department of Education
- All U.S. states - Longitudinal - Students in public schools

OSERS maintains a [data platform](#) on which the public can access IDEA-mandated demographic information about specific schools and school districts. The data set includes student enrollment and chronically absent percentages based on students' race, ethnicity, English Language Learner status, and whether they receive services as students with disability under the IDEA or Section 504. **This information does not include the number of students who use or need AAC.**

Additionally, OSERS provides data reported by school districts and states regarding students with disabilities, including infants and toddlers who receive early intervention services, as mandated by Section 618 of the Individuals with Disabilities Education Act (IDEA). This includes data about students identified in the primary IDEA disability category of "speech or language impairment." Some of the students in this category may need AAC, but many may not (U.S. Department of Education, [2022](#)). Students who need AAC are more likely to be categorized under one of the following out of the thirteen IDEA disability categories: Autism Spectrum Disorder (ASD), Intellectual Disability (ID), Traumatic Brain Injury (TBI), Multiple Disabilities (MD), Other Health Impairment (OHI), Orthopedic Impairment (OI), and Emotional Disturbance (ED).

National Beneficiary Survey (NBS)

⁴ A concern with this question is the use of the language "how effective at making themselves understood," placing the burden of effective communication solely on the individual with a speech disability.



- Social Security Administration (SSA)
- Office of Retirement and Disability Policy
- Federal - Every few years - SSI or SSDI beneficiaries, including group home residents

The SSA's Office of Retirement and Disability Policy conducts its own survey, known as the National Beneficiary Survey (NBS). The NBS provides the SSA, Congress, state legislators, and researchers with key data connected to Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) recipients' employment efforts. The agency has administered seven rounds of the NBS between 2004 and 2019 (Social Security Administration, [n.d.](#)).

The survey includes one question on speech-related communication difficulties, asking, "Do you have any difficulty having your speech understood because of a health condition or problem?" Those who respond in the affirmative are asked, "Are you able to have your speech understood at all?" Respondents are asked if they use "devices, equipment, or other types of assistance" for spoken communication, with responses including "voice synthesizer, voice amplifier, sign language interpreter, or other speech assistance" (Social Security Administration, [2019](#)).

B. STATE SOURCES

The **National Core Indicators** are a set of two surveys for adults 18 and over who receive certain state disability services. The first survey, NCI-IDD, is administered to adults with "intellectual and developmental disabilities," as their state of residence defines the term; the second, NCI-AD, is administered to adults who are "aging and disabled," as their state of residence defines the term.

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

In the 2020-2021 data collection cycle, the NCI-IDD had participation from 48 states, including California, along with 22 sub-state entities and the District of Columbia (National Core Indicators, [2021a](#)). Each state aims to survey at least 400 people with intellectual or developmental disabilities who receive at least one service from the state, with California surveying 8,648 in the 2020-2021 cycle, more than 10 times as many as any other individual state (National Core Indicators, [2021b](#)).



A question is asked on “preferred means of communication,”⁵ including spoken language, gestures, sign language, and communication devices. It is worth noting that 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.

Although the NCI-IDD does not survey all states, it is one of the most robust sources available for detailed, nuanced data on the lives and wellbeing of people with I/DD with speech disabilities who participate in public programs, and one of the few sources available that includes people living in institutions. Furthermore, the NCI-IDD prefers to collect information directly from the person they want to know about, allowing for proxy responses only under certain circumstances (National Core Indicators, [2021a](#)).

The primary weakness of the NCI-IDD in regards to the population of interest is its population limitation: only people receiving public developmental disability services are included. This excludes people with developmental disabilities who do not currently receive HCBS services from the survey. This group can include transition-age youth, persons on a waiting list, institutionalized persons, and any person who is regarded as having a developmental disability; the inclusiveness of that group may vary from state to state.

National Core Indicators—Aging and Disability (NCI-AD)

- Human Services Research Institute (HSRI)
- State Medicaid and disability agencies
- Participating states - Annual - Includes institutionalized people

The NCI-AD, like NCI-IDD, is a collaborative effort between the HSRI and state Medicaid and disability agencies. These organizations survey Medicaid and other public program beneficiaries to gain an understanding of the impact of services and of recipients’ quality of life (National Core Indicators, [2021c](#)). Although they have had the option to do so, until this year **no states have elected to ask NCI-AD participants about their usual method of communication**. During the 2022-2023 NCI-AD, respondents are asked about their preferred means of communication, i.e., spoken, gestures/body language, sign language/finger spelling, communication aid/device, or other. Results from this survey will be available in winter 2024.

⁵ 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.”



Consumer Assessment of Healthcare Providers and Systems Home and Community-Based Survey (HCBS-CAHPS)

- Centers for Medicare & Medicaid Services (CMS)
- Participating state Medicaid agencies
- Participating states - Annual

The HCBS-CAHPS is the first cross-disability survey on adults with all types of disabilities (e.g., physical, intellectual, developmental, brain injury, mental health, or substance use) who receive long-term services and supports from state Medicaid home and community-based services and supports programs. The multistate survey does not ask any relevant questions about speech or communication, and the only reference to AAC within the survey is an item about whether another person assisted the survey respondent through communication equipment (CMS, [n.d.e](#)).

Residential Information Systems Project (RISP)

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

RISP is a study of long-term services and supports for people with intellectual and developmental disabilities, led by the Institute on Community Integration at the University of Minnesota in collaboration with state I/DD agencies. RISP includes information on people with I/DD living in public residential facilities (RISP, [n.d.a](#)). RISP reported the proportion of respondents who “could not express their needs verbally” in 2016, but subsequent surveys in 2017 and 2018 do not appear to have asked about communication at all (RISP, [2016; n.d.a](#)).

C. CALIFORNIA SOURCES

California Health Interview Survey (CHIS)

- University of California, Los Angeles (UCLA)
- California Department of Public Health
- California Department of Health Care Services
- California - Annual - Institutionalized people excluded

UCLA administers the CHIS, the nation’s largest state health survey, in conjunction with the California Department of Public Health and the Department of Health Care Services. The CHIS claims to provide “policymakers, researchers, health experts, members of the media and others ...



credible and comprehensive data on the health of Californians.” It also asserts that it is “well known for its hard-to-find data on special subgroups and provides relatively robust samples of major racial/ethnic groups, sexual minorities, and other populations living in California” (UCLA Center for Health Policy Research, [2022](#)). The main health condition questions in the 2022 survey relate to asthma, COVID-19, diabetes, hypertension, heart disease, cancer and cancer screenings, nutrition, smoking (including vaping and hookah use), marijuana or cannabidiol use, prescription painkillers, methamphetamines, alcohol, sexual activity, pregnancy plans and use of birth control, HIV testing history, mental health, dental health, domestic violence, Internet use, experience with extreme weather events, and firearm possession.⁶ The CHIS also asks respondents whether they have been the victim of a hate crime based on their race or ethnicity, but not based on disability (UCLA Center for Health Policy Research, [2022](#), pp. 65).

The CHIS does ask survey respondents: “Are you blind or deaf, or do you have a severe vision or hearing problem?”⁷ But **the CHIS does not ask any questions about whether anyone in the family has a speech disability or has been evaluated for or been provided access to AAC.** Given that more than 20,000 Californians who are children, teenagers, and adults—from all 58 of the state’s counties—respond to the CHIS each year, the state should prioritize questions about how expressive communication needs may impact health (UCLA Center for Health Policy Research, [2022](#)).

The CHIS asks questions about “communication problems with a doctor,” which address difficulties understanding the doctor, language barriers, and access to interpreters. A person whose communication problems with a doctor are expressive but not receptive would not be identified through these questions, nor are reasons for difficulties other than speaking different languages disaggregated (UCLA Center for Health Policy Research, [2022](#), pp. 136-138).

California Client Development Evaluation Report (CDER)

- California Department of Developmental Services (CDDS)
- California - Annual - People living in state residential centers included

⁶ The CHIS also asks extensive questions about health insurance access and coverage.

⁷ This question is there as part of the old U.S. Census Bureau’s American Community Survey (ACS) set of disability measures. It has not been updated to a newer set since 2008.

The CDER is administered at least once every three years on the estimated 1% of the California population aged 3 or older with active status in the state’s Department of Developmental Services (DDS) system (California Department of Developmental Services, [2022](#)). Information is collected from the 21 regional centers throughout California as well as from residents of developmental centers, and includes people with a variety of developmental disabilities.⁸ In addition, the majority of Californians with developmental disabilities are not served by the DDS system due to California’s strict requirements for service eligibility and are therefore also not counted by the CDER. Specifically, California DDS services require disability onset by age 18, rather than the federal definition that uses age 22. California also limits eligibility to specific qualifying conditions (Mager-Mardeusz & Kominski, [2016](#)).

The CDER is divided into two major sections: the Diagnostic Element and the Evaluation Element. The Evaluation Element covers information relating to motor abilities, independent living, social, emotional, cognitive and communication skills (CDDS, [2022](#)). Three items in the CDER’s Evaluation Element are relevant to the population of interest (CDDS, [2022](#)):

- About the extent of “verbal communication” (item 12):
 - Does the person communicate with words?
 - Does the person communicate with words but speech is not easily understood by others?
 - Does the person communicate with simple statements and of how many words?
 - What is the extent of the person’s vocabulary?
- About the use of “nonverbal communication” (described as “if the person does not communicate with words) (item 13):
 - Does the person not use signals?
 - Does the person communicate via signals, gestures, signs, movement, or making eye contact?
 - Does the person not only use but understand others’ signs, gestures, or facial expressions in communication?
- About the extent of “social interaction” (item 14):
 - Does the person engage in interaction with others?
 - Does the person initiate interaction with others and in what context?

⁸ *Regional centers* are nonprofit, community-based agencies in California that, in addition to providing assessments, offer case management services, determine service eligibility, and may create, buy, and organize services within a person’s individualized plan. *Developmental centers* are state-operated residential facilities. Eligibility for regional center services requires that a person’s disability began prior to the individual’s 18th birthday and “is expected to continue indefinitely and present a substantial disability” (CDDS, [2022](#)).



The CDER is the only California-specific data source that currently attempts to explicitly count a portion of the population of interest. However, there are several significant issues that prevent it from actually doing so.

First, it is not clear how a person who uses language-based AAC would be classified by the CDER. Item 12 (“verbal communication”⁹) asks whether the person communicates “us[ing] words,” but sign language, many forms of AAC, and speech all use words. In addition, the description for item 13 (“nonverbal communication”¹⁰) refers to the subject’s use of “specialized devices,” which suggests that someone who uses language-based AAC should *not* be counted under item 12 (California Department of Developmental Services, 2022).

Yet the possible responses to item 13 do not actually include “the use of specialized devices,” asking instead only about whether the subject uses “signals,” “gestures,” “signs,” “movement,” “smiling,” “making eye contact,” “pointing,” “shaking head,” “leading by the hand,” and “facial expressions” to communicate (California Department of Developmental Services, 2022). Although these questions do not leave a space for Californian AAC users to be counted, they may represent a useful way to measure the number of people who need but lack access to language-based AAC.

Second, while attempted distinction between receptive and expressive communication is theoretically helpful, the survey is constructed in a way that may conflate the concepts. For example, two of the possible responses to item 12 are: “Uses sentences of three words or more and has a limited vocabulary (30 words or less),” and “Uses sentences of three words or more and has a vocabulary of more than 30 words” (California Department of Developmental Services, 2022). But it is one thing to “have a vocabulary” (which, in common parlance, implies *understanding*), and another thing entirely to be able to *express* that vocabulary.

Third, these questions assume that a single response will adequately characterize a subject. But for many AAC users, several of the response options to items 12, 13, and 14 would accurately describe the subject. For instance, in item 12, many people with cerebral palsy would likely answer “yes” to both, “Uses words to communicate, but speech is not easily understood by strangers,” and “Uses sentences of three words or more and has a vocabulary of more than 30 words.”

⁹ The description of “verbal communication” for the surveyor is “Use of words to ask for something or to indicate needs” (California Department of Developmental Services, 2022). This excludes people who use words for other topics but not needs and requests.

¹⁰ The description of “nonverbal communication” for the surveyor is “Communication through means other than words, including the use of specialized devices that allow or facilitate communication” (California Department of Developmental Services, 2022), although many “specialized devices” used for AAC do use words.



To accurately collect data on California’s population receiving services from the Department of Developmental Services, the CDER must revise the section on communication to represent people who need AAC.

D. INTERNATIONAL SOURCES

Canada’s Participation and Activity Limitation Survey (PALS)

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

Canada’s **Participation and Activity Limitation Survey (PALS)** asked about communication disability, defined as “difficulty speaking and/or being understood,” for both children and adults. However, the Canadian Survey on Disability (CSD), which replaced the PALS in 2012, no longer asks about communication disability (Cloutier, Grondin, & Lévesque, [2018](#)).

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

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

The Australia Bureau of Statistics (ABS) **Survey of Disability, Ageing, and Carers (SDAC)** gathers data on communication disability, but unfortunately confounds this data with other unrelated disabilities. Adults may report that they have a disability “affecting core activities, including communication, mobility, or self-care.” The proportion of children with a “sensory or speech disability” is also reported. Autistic people are the only group able to report their speech-related communication needs in greater detail, including whether they need assistance, whether the need is at least daily, and whether they need more help than they are currently receiving. Caregivers are also able to report if they provide communication support to the main person they assist (Australian Bureau of Statistics, [2019](#)).

In summary, the vast majority of surveys at the state, federal, and international level do not collect any data on significant speech disabilities. When surveys do have questions related to the population of interest, the results generally fail to provide accurate or complete estimates. Current survey questions are designed in such a way that make it impossible to determine how many people in the U.S. use and need AAC. The ACS, the most widely used survey for disability research in the United States, does not identify people with speech disabilities, making it

AAC COUNTS

impossible to use its rich dataset in counting people who need AAC. In order to truly achieve data equity with other disability populations, surveys must design questions that are worded in ways that are inclusive for all who need AAC.

III. Considerations in Counting and Surveying People Who Need AAC

When people lack access to AAC, it makes it difficult for them to participate in surveys. As a result “proxies” are often used to answer survey questions on their behalf. A proxy data source is a supposedly knowledgeable third party who responds on behalf of an individual who is presumed to be unable to respond for themselves.¹¹

But these supposedly knowledgeable third parties do not necessarily know the true concerns and priorities of the person who needs AAC. The validity of proxy responses is questionable, especially when it comes to questions surrounding quality of life, which are often highly subjective, personal, and potentially sensitive (Kaye, 2007). Furthermore, studies have shown that proxy reports of disability tend to underreport disability for young people and overreport disability for people over 65 (Todorov & Kirchner, [2000](#)).

In the 1994-1995 Phase II of the National Health Interview Survey on Disability (NHIS-D), also known as the Disability Followback Survey, surveyors were, for the first time, provided training on how to interact with disabled people. Self-response was encouraged whenever possible. In Phase I, 27.6% of responses involved a proxy; in Phase II, this figure was reduced to 12.9%, with 4.8% of respondents utilizing what is known as “assisted response.” The rate of proxy response varied between groups of people with different impairments, but some of the highest rates were found in people with significant speech disabilities (defined as those whose speech is difficult to understand even by family members), at 56.5%. People with moderate speech disabilities (defined as those whose speech is difficult to understand by people outside their family) utilized proxy responses at a rate of 47.7%. People with significant speech disabilities also had the lowest rates of assisted response at 1.5% (compared to 4.5% for moderate speech disabilities) (Kaye, 2007).

Assisted response has not been used in disability surveys since the Disability Followback Survey, but with appropriate training and safeguards, it may be a tool for surveyors to consider to increase the validity and accuracy of surveys about people who need but lack AAC (Kaye, 2007).

¹¹ For example, CDER administrative data is reported by a “knowledgeable person,” who would usually be “someone who has directly observed the consumer’s daily behavior for at least one week within the preceding six months” (California Department of Developmental Services, [2022](#)). This could be a relative or a disability professional, but it is not clear if or when this might be the person with a developmental disability themselves.

Other strategies can be developed that support non-speech responses for people who need but do not have AAC. In-person interactions between the individual and interviewer will help the interviewer become familiar with the individual's style of communication. The interviewer should also get to know someone close to the individual who knows their communication style well.

Determining consent may be a thorny issue when it comes to surveying people who lack AAC. While it is important to ensure potential participants are not coerced into survey participation by either researchers or guardians, it is just as important to ensure that people who can participate are not excluded from doing so by virtue of a cognitive limitation, real or assumed. This is particularly important in the context of the population of people who need AAC, where people without access to AAC or speech are often wrongly assumed to be completely incapable of providing consent on the basis of their speech disability alone, regardless of other factors.

For people who need and have AAC, accommodations may still be necessary. AAC users should be asked about their preferred environment and circumstances for communication. In some cases, an assisted response team consisting of the AAC user and someone very familiar with their communication style may reduce miscommunication or provide helpful context. Ultimately, the AAC user should dictate the terms of engagement.

Researchers should be aware of vocabulary, both in terms of using respectful language (McDonald et al., [2022](#)) and in avoiding difficult or imprecise vocabulary, which may make it harder for some to understand the survey (Diaz et al., [2021](#); McDonald et al., [2022](#); Nicolaidis et al., [2020](#)).

Given the diversity of people who need AAC, it will be difficult to accommodate a wide variety of sometimes conflicting access needs in designing surveys. Given these conflicts, incorporating flexibility into the design of the survey, including how questions are asked and responses recorded, is paramount (McDonald et al., [2022](#)). This includes, for example, allowing open response explanations for answers for the benefit of autistic respondents who prefer precision (Nicolaidis et al., [2020](#)), but not requiring them; this avoids causing problems for people with dementia or aphasia, who may struggle with a lot of writing or typing to explain themselves (Diaz et al., [2021](#)). Surveys will ideally incorporate multiple administration methods, such as in-person interviews, video conference interviews, paper, telephone,¹² and web-based responses.

Researchers and surveyors have only begun to scratch the surface when it comes to developing techniques that make self-report possible for populations whose voices have historically been replaced in research by proxies. Community-based participatory research (CBPR) design meaningfully includes members of the target population and draws from their lived experience to

¹² Telephones are not accessible for all AAC users.



understand best research practices for that population (Raymaker & Nicolaidis, 2013; Diaz et al., [2021](#); Donaldson, corbin, & McCoy, [2021](#)). Flexibility, creativity, and expert panels guided by community members continue to lead to new developments in accessible and accurate self-reporting and research overall (see Fujiura & RRTC Expert Panel on Health Measurement, [2012](#); Shogren et al., [2021](#); McDonald et al., [2022](#)).