



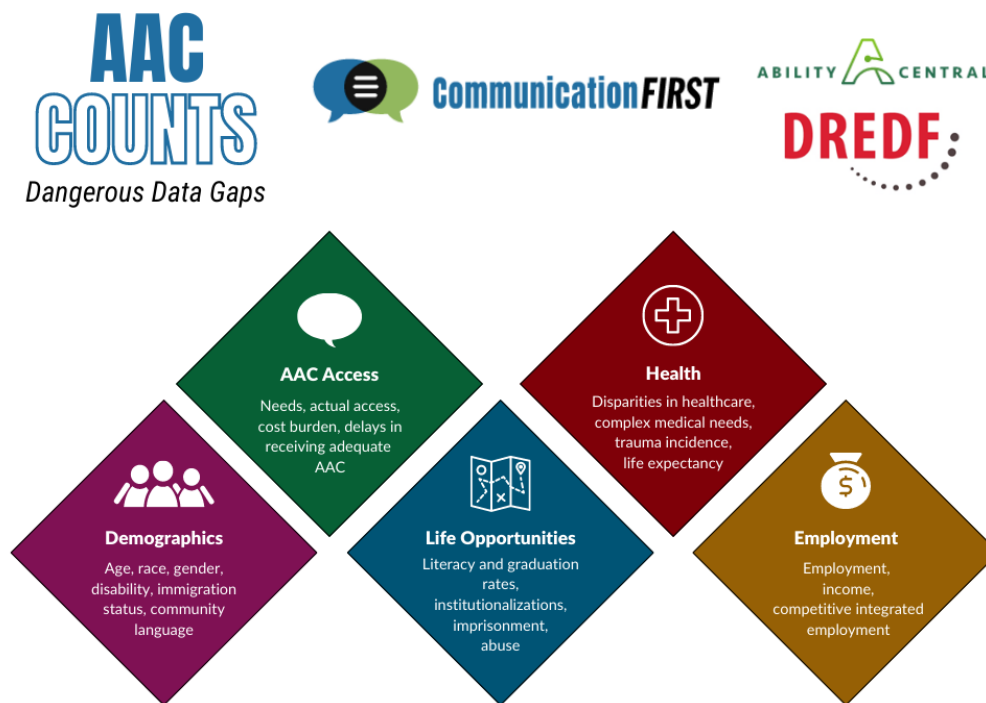
Appendix B

List of Data Needs

This document contains a non-exhaustive list of the data that are necessary to begin to better understand the demographic characteristics and needs of people who need augmentative and alternative communication (AAC) in the United States.

Demographic and characteristic data collected must be comprehensive and able to be disaggregated in order for policymakers in different agencies and jurisdictions to adequately assess and address disparities and unmet needs (Swenor, 2022).

We also believe that data longevity, harmonization, and continuity is paramount for our community, given that our population and our needs are constantly evolving (Mont et al., 2022). **Sustainable funding structures to enable longitudinal data collection and reporting should therefore be identified with continuity in mind.**



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A. DATA THAT A REVISED AMERICAN COMMUNITY SURVEY COULD REVEAL

- What is the size of this population?
- What are the characteristics of this population, including age, gender, race, ethnicity, language used in the home, other disabilities, and socioeconomic status?
- How many are married?
- What percentage of students who needed AAC in the past year:
 - ...graduated from high school with a standard diploma?
 - ...attended college?
- What percentage of people who needed AAC in the last year:
 - ...were employed full-time or 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), 100-300%, or >300% of the FPL?
 - ...received SSI, SSDI, Social Security Retirement, or TANF benefits?
 - ...resided in integrated community, group homes, or institutional (including juvenile justice and adult corrections) settings?
 - ...had public or private health insurance, or were uninsured?

B. DATA OTHER AGENCIES COULD COLLECT

U.S. Centers for Disease Control and Prevention (e.g., through the NHIS and BRFSS)

- What percentage of people who need AAC continue to lack access to it?
- Are there gender, racial, language, or economic disparities in accessing AAC?
- How many have opportunities to experience romantic relationships or have meaningful friendships?
- What percentage of people who need AAC received or reported an unmet need to access Medicaid home and community-based (HCBS) or institutional long term services and supports (LTSS)?

U.S. Department of Justice

- What percentage of people who need AAC experienced disability-related bullying, harassment, sexual violence, abuse, neglect, exploitation, violence, threats, or substantial harm?



U.S. Department of Education

- What percentage of students who need AAC:
 - ...are educated in fully inclusive settings versus more restrictive settings?
 - ...have access to sufficiently robust AAC to effectively communicate and to receive an equal education?
 - ...are reading at or above grade level?
 - ...graduated or otherwise left public school with the AAC they need to effectively communicate, and the requisite literacy skills to do so?

U.S. Department of Health and Human Services

- How many people who need AAC receive health coverage through Medicare, Medicaid, the Children's Health Insurance Program (CHIP), and/or Health Exchange programs?

C. DATA NEEDS LISTED BY POLICY DOMAIN

1. Access Needs

- a. Access to AAC
 - i. Duration of time between AAC need identified and AAC accessed
 1. Whether that duration varies by age (e.g., school age vs. working age adult vs. elderly), disability type (e.g., ALS vs. autism), race, primary language, gender, geographic location, residence type, family income, other characteristics
 - ii. Types of AAC accessed/provided
 - iii. Whether or not the types of AAC tools and supports provided meet communication needs
 - iv. Percentage who need, have trained communication support providers
 1. Publicly vs. privately funded
 2. Qualifications and training of the communication support provider
 - v. Cost of providing the AAC (including training, coaching, repair, maintenance, and any necessary ongoing human support)
- b. Access to various types of health care (e.g., mental health, oral health, sexual health, addiction services, and organ transplants)

2. Residential Characteristics

- a. Setting of residence (i.e., urban, suburban, rural, or reservation setting)
- b. Living arrangements / Type of residence (i.e., home, apartment, group home, child welfare or foster care, long-term institution, short-term institution, incarcerated, unhoused)



- i. Of the fewer than 18,000 people remaining in institutions, what percentage need and use AAC

3. Social Services Need and Utilization

- a. Entitlement benefits received (e.g., SSI/SSDI, Medicare, Medicaid, food/transportation benefits)
 - i. Do these benefits adequately meet their needs?
- b. Specific disability services (e.g., vocational rehabilitation, job supports)
- c. Percentages receiving Home and Community-Based Services (HCBS)
 - i. Percentages on waitlists
 - ii. Percentages accessing communication support providers through HCBS
- d. Percent accessing other federally-administered health plans (e.g., Tricare, Veterans Affairs, Indian Health Service)

4. Health Status and Outcomes

- a. Life expectancy
 - i. How life expectancy compares with others with the same primary disability type who do not need AAC
- b. Rates of accidents experienced
- c. Rates of abuse reported
- d. Rates of complex medical needs / chronic conditions
- e. Rates of experiencing a health risk such as smoking, drinking, or food insecurity
- f. Rates of mental health conditions (including suicidality or self-harm)
- g. Rates of trauma

5. Guardianship/Conservatorship

- a. Percentage subject to guardianship / conservatorship
 - i. Percentage who consented to termination of their rights
 - ii. Number who have terminated their guardianship

6. Education

- a. Prevalence / rates in early intervention, preschool, K-12, and higher education
- b. AAC access rates
 - i. Rates of graduating (or otherwise leaving) public school with the AAC necessary to effectively communicate
- c. Literacy rates
- d. Dropout rates
- e. Graduation rates by diploma type
- f. Educational services received



- i. Qualifications of service providers, including AAC training
 - g. Gifted identification rate
 - h. Rate of inclusive versus segregated placements, homeschooling, other school settings
 - i. Percentage experiencing seclusion or restraint
 - j. Percentage participating in extracurricular activities
 - k. Percentage enrolling in, graduating from college (technical, associate's, bachelor's, graduate, professional degree programs)
- 7. Immigration Status and Language Barriers**
 - a. Percentage of non-citizens, including undocumented status
 - b. Percentage who are multilingual
- 8. Voting**
 - a. Percentage registered
 - b. Percentage that actually votes
 - c. Percentage using mail-in or early voting options
 - d. Percentage experiencing barriers to registering to vote and voting
- 9. Marriage, Family Circumstance, and Social Support Networks**
 - a. Marriage and family status
 - i. Percentage who are married or in long-term relationships
 - ii. Percentage who are parents (including by adoption)
 - b. Adoptee population
 - c. Percentage who feel they have the opportunity to have meaningful friendships and romantic relationships
- 10. Employment**
 - a. Employment and unemployment rates
 - b. Average wages
 - c. Status of competitive integrated employment
 - i. Kinds of jobs worked
 - ii. Full-time vs. part-time
 - iii. Accommodations
 - iv. Access to internships
 - v. Supported employment rates
- 11. Income, Poverty, and Wealth**
 - a. Average annual income

AAC COUNTS

- b. Proportion with earnings at or above the median income level for where they live
- c. Proportion with income at or below the federal poverty level (FPL), 100-300% of FPL, or >300% of FPL
- d. Home ownership rates
- e. Estimated financial burden of speech-related disability / provision of AAC on family finances

12. Criminal Justice

- a. Experience with bullying and harassment
- b. Victimization rates (nonviolent and violent)
- c. Type of victimization
 - i. Child abuse, neglect, or exploitation, including missing children and runaways
 - ii. Sexual violence
 - iii. Human trafficking
 - iv. Murder
 - v. Hate crimes
 - vi. Restraint/seclusion
 - vii. Police violence
 - viii. Adult neglect and abuse, including physical, sexual, emotional/verbal, and financial
- d. Number and type of crimes involving AAC users reported, investigated, charged, prosecuted, convicted
- e. Number of AAC users who have testified in formal judicial proceedings as defendant, witness, or victim
- f. Population that has experienced a crime that was not investigated because they were “unable to be interviewed”
- g. Population currently in jail or prison
 - i. AAC access issues for incarcerated population
 - ii. Average sentence served