

Appendix D

Key National Sources of Demographic, Disability, and Health Data

	<i>Frequency</i>	<i>Type</i>	<i>Relevant Data Collected</i>	<i>Stakes</i>
American Community Survey (ACS) (U.S. Census Bureau)	Annual	Large-scale population survey on demographics and population Includes institutionalized and noninstitutionalized people	None	Determines distribution of more than \$675 billion in federal and state funds annually Makes clear how well disability civil rights laws and decisions are being enforced
National Health Interview Survey (NHIS) (U.S. Centers for Disease Control and Prevention (CDC))	Annual	Large-scale population survey focusing on health and disability Face-to-face household interviews Noninstitutionalized civilians only	Adults: “Do you have difficulty understanding or being understood?” Children: “Do they have difficulty being understood by family members?” “Do they have difficulty being understood outside of family?” Does not ask about AAC access	Main source of health data in U.S. Monitors health trends and tracks progress towards national health goals Enables researchers to determine barriers to care Enables effective evaluations of federal health programs
National Health Interview Survey Supplement on Voice, Swallowing, Speech, and Language Problems (CDC)	Performed once in 2012 and again in 2022	Part of NHIS Noninstitutionalized civilians only	2012: Population, etiology, frequency, duration, severity, age of onset, services/care received, effect of care on quality of life, change over time	Largest-scale population survey to date gathering specific information on people with speech disabilities

			2022: No longer asks about etiology, duration, or age of onset Does not ask about AAC access	
National Health and Nutrition Examination Survey (NHANES) (CDC)	Annual	Survey combining interviews and physical examinations, focusing on health	Asks whether respondent has difficulty being understood inside and outside the home Does not ask about AAC access	Provides important public health statistics and information on health risks and disease prevention
Behavioral Risk Factor Surveillance System (BRFSS) (CDC)	Annual	Telephone survey on health behavior	None	Collects data on health risks , chronic conditions, and access to care
National Survey of Children's Health (NSCH) (Health Resources and Services Administration)	Annual	Mail and web-based survey of children's health, including children with serious disabilities or complex medical needs	Asks whether a parent has ever been told that their child has a speech or language disorder, and if so, its severity Does not ask about AAC access	Explores factors relevant to children's wellbeing , guiding parents, researchers, and community health providers
Survey on Income and Program Participation (SIPP) (U.S. Census Bureau)	Annual	Longitudinal household interview survey on income dynamics and participation in government programs	None after 2014	Ensures that government programs are working as intended Evaluates measures of poverty , including income, health

				insurance, food security, and more
All of Us (NIH)	Longitudinal	Online survey on health designed to maximize diversity in studied population	None	Aims to understand risk factors for negative health outcomes and guide treatment best practices
National Health and Aging Trends Survey (NHATS) (NIH)	Longitudinal	Survey of adults 65 and older receiving Medicare Institutionalized adults do not receive the sample person interview, although the facility questionnaire is still completed	Asks about trouble speaking or making self understood when speaking Does not ask about AAC access	Aids in understanding the process of becoming disabled late in life
Transformed Medicaid Statistical Information System (T-MSIS) (CMS)	Monthly	Administrative data set on Medicaid and CHIP claims	None	The largest national resource of beneficiary information Helps ensure Medicaid and CHIP are working as intended
National Beneficiary Survey (NBS) (SSA)	Every few years	Survey of individuals who receive SSI or SSDI, including residents of group homes	Asks about difficulty having speech understood Does not ask about AAC access	Aims to improve SSI and SSDI programs
Minimum Data Set (MDS) (CMS)	Quarterly	Administrative data set, including direct assessment, of residents of Medicaid- and Medicare-certified nursing homes	Asks about speech clarity and residents' ability to make their needs and wants understood Does not ask about AAC access	Ensures quality of nursing homes for residents of all ages and abilities



IDEA Data Center (OSERS, U.S. Department of Education)	Longitudinal	IDEA-mandated administrative data set on children with disabilities in the public school system	None	Used to ensure that children with disabilities are receiving an equal free appropriate public education
National Core Indicators—Intellectual and Developmental Disabilities (NCI-IDD) (NASDDDS and HSRI, in collaboration with participating state I/DD agencies)	Annual	Survey of people with I/DD who receive at least one state I/DD service Includes institutionalized people	Asks about “preferred” means of communication, including various non-speech methods Does not ask directly about AAC access	Measures and improves the performance of public developmental disability agencies Collects rich data on wellbeing and quality of life
National Core Indicators—Aging and Disability (NCI-AD) (HSRI, in collaboration with participating state aging and disability agencies)	Annual	Survey of people receiving at least one service from aging and disability agencies in their state	None, although states could choose to ask the NCI-IDD question on communication	Assesses services provided to individuals and their families
Consumer Assessment of Healthcare Providers and Systems Home and Community-Based Survey (HCBS-CAHPS) (CMS, in collaboration with participating state Medicaid agencies)	Annual	Survey of people receiving Medicaid HCBS long-term services and supports	None	Compares HCBS programs across the country across many different disabilities
Residential Information	Longitudinal	Study of long-term services and supports	None since 2016	Provides data to assess Medicaid-

AAC COUNTS

Systems Project (RISP) (State I/DD agencies)		for people with I/DD, including community- and institution-based		and state-funded long-term services and supports Assesses living conditions of institutions
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