

Appendix C

Table of Existing Prevalence Data by Disability or Condition

This table below provides high-level estimates of the number of people in the United States with significant speech-related disabilities that may cause or contribute to a need for augmentative or alternative communication (AAC), organized by diagnosis or condition. These estimates are calculated from existing literature from each diagnostic community. Methods used differ, and not all of the following figures can be assumed to be reliable and accurate estimates.

Moreover, while understanding which diagnoses relate to significant speech disabilities is important for understanding the makeup of the population, it is equally important to understand that diagnostic labels do not define this group of people, that some people who need AAC may never be diagnosed with any specific condition, and that the population should be counted and understood beyond their diagnostic categories.

	Onset	Estimated U.S. Population (Total)	Estimated Percentage with AAC Need	Estimated U.S. Population with AAC Need
Amyotrophic lateral sclerosis (ALS)	Acquired, progressive	16,500 (Mehta et al., 2018)	80% will lose the ability to speak (Brent et al., 2020)	13,200
Angelman syndrome	Birth	5,000 (Williams, 2014)	100%	5,000
Aphasia	Acquired, stable	2.5 million (Simmons-Mackie et al., 2018)	100%	2.5 million
Autism	Birth	10.4 million (Li et al., 2022)	30% (Anderson et al., 2007)	3.125 million
Childhood apraxia of speech	Birth	111,300 (Shriberg et al., 1997)	100%	111,300
Cerebral palsy	Birth	176,000 (CDC, n.d.)	35% (Anderson et al., 2010)	61,600
Dementia and Alzheimer's	Acquired, progressive	2.4 million (CDC, 2012)	Unknown	Unknown

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Down syndrome	Birth	250,700 <i>(Presson et al., 2013)</i>	15%	37,500
Friedrich ataxia	Acquired, progressive	6,635 <i>(NINDS, 2016)</i>	Unknown	Unknown
Huntington's disease	Birth, progressive	41,467 <i>(Yohrling, 2020)</i>	Unknown	Unknown
Multiple sclerosis	Acquired, stable or progressive	1 million <i>(National MS Society, n.d.a)</i>	40% <i>(National MS Society, n.d.b)</i>	400,000
Parkinson's disease	Acquired, progressive	930,000 <i>(Marras et al., 2018)</i>	90% <i>(Buck, 2019)</i>	837,000
Selective mutism	Usually acquired	2.04 million <i>(Viana et al., 2009)</i>	Unknown	Unknown
Tracheostomies or prolonged ventilator use	Usually acquired	82,350 <i>(Mehta et al., 2015)</i>	100%	82,350
Traumatic brain injury	Acquired	5.3 million <i>(CDC, 2015)</i>	Unknown	Unknown
U.S. TOTAL (ESTIMATED)				at least 7,173,320

Other diagnoses that may cause a need for AAC, but which lack population estimates, include aphonia, acquired apraxia of speech, cleft lip and/or cleft palate, congenital disorders of glycosylation, Cri du Chat syndrome, dysarthria, dystonia, laryngeal cancer, laryngectomy, locked-in syndrome, muscular dystrophies, myalgic encephalitis/chronic fatigue syndrome, primary progressive aphasia, rare genetic syndromes, Rett syndrome, spasmodic dysphonia, and Tourette syndrome. People with temporary conditions that make speaking difficult may also need AAC for the duration of their condition.