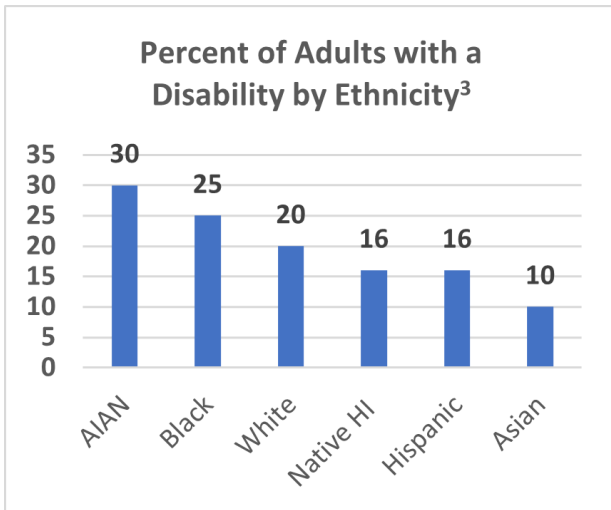


Living with Disability

WHO IS LIVING WITH A DISABILITY?

People with disabilities are the largest minority group (12.7%) in the United States and the only group any of us can become a member of at any time⁷. In 2019, there were 41 million people with disabilities in the U.S.¹

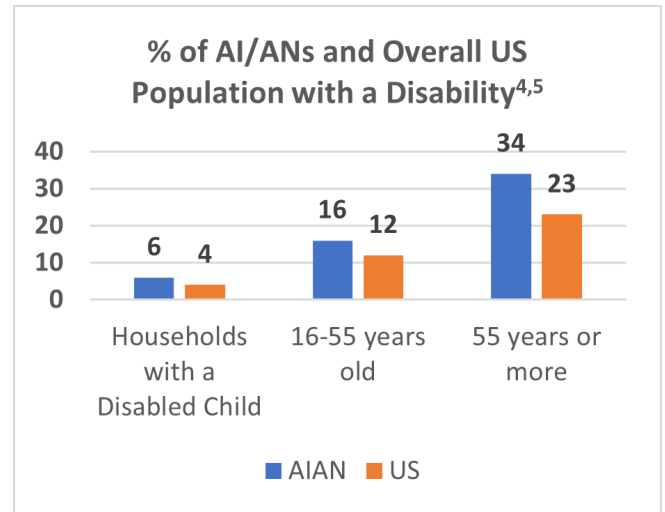
Data from the Centers for Disease Control and Prevention in 2020 found that 30%, or one in three, American Indian or Alaska Native (AI/AN) adults have a disability and that Native people overall are 50.3% more likely to have a disability when compared to the national average.²



WHAT IS A DISABILITY?

A disability is any condition of the body or mind (**impairment**) that makes it more difficult for the person with the condition to do certain activities (**activity limitation**) and interact with the world around them (**participation restrictions**).⁶

Disabilities can be visible or unnoticed by others. A disability can begin as a condition from birth or result later in life from injury or disease. The likelihood of living with a disability increases with age.



According to the CDC, disability has three dimensions:⁶

1. An **impairment** exists within a person's body or mental functioning such as loss of a limb, vision, or memory.⁶
2. An **activity limitation** makes it difficult to perform a task such as seeing, hearing, walking, or problem solving.⁶
3. **Participation restrictions** impede a person's involvement in life situations such as working, socializing, recreating, obtaining health care, and preventive services.⁶

WHAT IS INCLUSION?

Inclusion means everyone can fully participate in society. Policies and practices are designed to identify and remove physical, communication, and attitudinal barriers.⁷ An inclusive society is one that is accessible and provides reasonable accommodations and assistive technology.

Accessibility means products, services, and facilities can be used by people of all abilities. For example, physical spaces are modified or

designed with wheelchair ramps, power doors, curb cuts, talking streetlights, braille signage, etc. To facilitate communication, fire alarms are seen and heard; screen readers are available on electronic devices, and closed captioning is available on television, etc.

An inclusive attitude recognizes what a person can do rather than a person's disabling condition. It is the belief that people with disabilities can do things and make their own decisions.

Reasonable accommodations are alterations to items, procedures, or systems that enable a person with a disability to use them to the maximum extent possible.⁷ For example, people with a visual impairment have alternative texts provided such as braille, large print, or audiobooks. People with a hearing impairment may have an American Sign Language interpreter or exchange written messages with someone.

Assistive technology (ATs) are devices, tools, or equipment that enhance functional independence and make daily living easier.⁷ ATs can be simple or complex. Button hooks or canes are simple tools. Smart (talking) canes or gaze interaction computers (navigated by a user's eye control) are complex devices.



WHAT DOES INDEPENDENT LIVING MEAN FOR A PERSON WITH A DISABILITY?

Independent living means that people with disabilities have a voice, choice, and control over their everyday lives.⁷ A person may not need any assistance and may live, work and travel without help. Others may need help with managing money, and day-to-day living skills like cleaning the house, cooking, shopping, using transportation, etc.

WHAT IS ADVOCACY AND ALLYSHIP?

Advocacy promotes the interests or causes of someone or a group of people. Self-advocacy is speaking up for yourself by expressing your interests, desires, needs, and rights. Individual advocacy, also called allyship, is having someone stand beside you (an ally) who speaks out for change on behalf of another person or group. Systems advocacy is done by individuals and/or organizations that work to change policies, laws, or rules that unfairly impact a group⁸.

CARE AND SUPPORT FOR PEOPLE WITH DISABILITIES

When caring for a person with a disability, it's essential to have a greater understanding of what it is like for that person to live with a disability. Knowing the individual, their culture, values, and how they perceive their condition and abilities are equally important.

Conditions usually occur along a spectrum so that two people with the same impairment – loss of vision, for example – may have very different levels of function, and need varying levels of care and support, while others may have other co-occurring conditions, often called, “comorbidity.”

Medical professionals, as well as family members and caregivers, should provide services and support to help people with disabilities maintain their dignity and independence.

Services and support should offer a person-centered approach, which emphasizes listening and respecting the individual's preferences, needs, and values. If a person's condition is likely to progress or impact their ability to problem solve or communicate, advance care planning and directives can ensure that their wishes are in writing.

DISABILITY IN INDIAN COUNTRY

People with disabilities in Indian Country are often unserved or underserved. Tribal communities face numerous barriers, including lack of funding, employment opportunities, day programs for adults living with developmental disabilities, staff, transportation, coordination among agencies, consultation with tribes, cultural sensitivity by non-Native staff, and systems to identify people eligible for services.⁹

To meet the needs of AI/ANs living with developmental and/or acquired disabilities, there are four areas that can improve support and services:

1. Prioritize home and community-based services that may offer culturally appropriate care for AI/ANs with disabilities
2. Listen to the voices of AI/ANs receiving Long-Term Services and Supports (LTSS)
3. Provide trauma-informed care
4. Consider the needs of family caregivers who provide a majority of LTSS in Indian Country¹⁰

AI/ANs living with disabilities deserve equal access, reasonable accommodations, and an opportunity to make powerful contributions to their society. Indian Country is known for making room for everybody.

What you can do to help is look at your community and make it more accessible to our Elders and others living with disabilities. Be an ally and advocate for making life easier for everyone.

Contact NICOA to learn more:
www.nicoa.org | 505-292-2001

SOURCES

¹ 2020 Annual Disability Statistics Compendium. (2020). <https://disabilitycompendium.org/compendium/2020-annual-disability-statistics-compendium?page=6>.

² "AI/AN Age and Disability." (December 1, 2021). Centers for Disease Control and Prevention. Accessed 2 July 2021. <https://www.cms.gov/Outreach-and-Education/American-Indian-Alaska-Native/AIAN/LTSS-TA-Center/info/ai-an-age-and-disability>.

³ "Adults with Disabilities: Ethnicity and Race." (September 16, 2020). Centers for Disease Control and Prevention. Accessed 2 July 2021. <https://www.cdc.gov/ncbddd/disabilityandhealth/materials/info-graphic-disabilities-ethnicity-race.html>.

⁴ Young, Natalie A.E. "Childhood Disability in the United States: 2019." U.S. Department of Commerce: U.S. Census Bureau, American Community Survey Briefs, March 2021. Accessed 1 July 2021. <https://www.census.gov/content/dam/Census/library/publications/2021/acs/acsbr-006.pdf>.

⁵ U.S. Bureau of Labor Statistics. "American Indians and Alaska Natives in the U.S. Labor Force," November 2019. Accessed 6 October 2021. <https://www.bls.gov/opub/mlr/2019/article/american-indians-and-alaska-natives-in-the-u-s-labor-force.htm>.

⁶ "Disability and Health Overview." (Sept.16, 2020). Centers for Disease Control and Prevention. <https://www.cdc.gov/ncbddd/disabilityandhealth/disability.html>.

⁷ "Disability and Health Inclusion Strategies." (September 15, 2020). Centers for Disease Control and Prevention. <https://www.cdc.gov/ncbddd/disabilityandhealth/disability-strategies.html>.

⁸ "Types of Advocacy." (No date.) West Virginia University Center for Excellence in Disabilities. <https://cedwvu.org/resources/types-of-advocacy>.

⁹ National Congress of American Indians, Disabilities, retrieved July 12, 2017. <https://www.ncai.org/policy-issues/education-health-human-services/disabilities>.

¹⁰ "Improving Care for Adults with Disabilities in Indian Country: Highlights from the Literature." (December 15, 2018). Department of Health and Human Services, Centers for Medicare and Medicaid Services. <https://www.cms.gov/Outreach-and-Education/American-Indian-Alaska-Native/AIAN/LTSS-TA-Center/pdf/LTSS-Highlights-from-Literature-Disabilities.pdf>.

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