Unlike race, ethnicity, and age, disability is not a standard demographic status, leading to a global lack of data on people with disabilities. This lack of data contributes to:

- an underrepresentation of disabilities in official statistics, causing policymakers to frequently disregard the needs of disabled people; and
- poses challenges in identifying these needs, resulting in a scarcity of comprehensive programs and services to address them.

Currently, in the United States, many federal agencies track disability data, however the efforts are limited by gaps in specific tabulations, varying approaches to classifying disability, and poor engagement with the population of people with disabilities.

- The multitude of ways people can define or identify with a disability leads to inconsistent or incompatible data.
- While it is not possible to create a universal definition, disability status should be a standard demographic question, and should be asked in a way that makes data more comparable across data sets.

Why is data important to health equity?

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What data do we currently have?

16% of Maine’s population has one or more disabilities.

This is higher than the United States as a whole, where an estimated 13% of residents have a disability.

Piscataquis County, the least populated county in Maine, has the highest percentage of people with disabilities (26%).

The US Census Bureau’s American Community Survey’s survey design provides estimates of disability characteristics that draw from smaller sample sizes, resulting in higher margins of error (the degree of uncertainty results may have).²

Issues in survey design, access to healthcare, and stigma and discrimination lead to challenges in collecting accurate and representative data on disability and health.
**Recommendations**

1. Make disability status a standard demographic indicator in data collection and surveillance efforts.

2. Data on individuals with disabilities should be relevant, up-to-date, and accessible.

3. Individuals with disabilities must be represented in public health surveillance efforts.

**References:**

1. From the US Census Bureau: The civilian non-institutionalized population are those persons 16 years of age and older residing in the 50 states and the District of Columbia, who are not inmates of institutions (e.g., penal and mental facilities, homes for the aged), and who are not on active duty in the Armed Forces.


**For more information:**

www.drme.org/news/2022/health-equity-at-drm